

School of Nursing and Midwifery

**The Lived Experience of Bedwetting in Western Australian Male
Youth**

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material that has been accepted for the award of any other degree or diploma in any university.

Signed:

Date:

Acknowledgements

Dedication

This thesis is dedicated to the six young men who so bravely shared their stories, often with a tear in their eye, but as expressed by all, with hope in their hearts that others would be spared this chronic disabling problem.

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There is one pivotal person behind this research who without his encouragement, support and sometimes challenging and differing opinions, the subject would continue to remain “hidden”. Mr Z. S. Wisniewski (Stan) a thank you for your continued interest over the past 20 years – from the pilot study on the subject that we initiated in 1996, supported by 5th year medical students from the University of Western Australia. You are, and continue to remain inspirational in my professional life.

Ness, thank you for your story and the empathy and love you showed, when in 1987, (14 years old) you befriended a student (unknown to you), because she was standing alone (strong urine odour) in the school grounds at the recess breaks.

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Abstract

This phenomenological study describes the lived experience of young men who have persistent bedwetting and live in the Western Australian community. The objectives of the research were to explore and describe these experiences and to set them within the context of existing literature. A purposive sample of six young men agreed to participate in this study and data were collected using semi-structured interviews.

The findings revealed that all of the participants, aged between 19 and 27 years used *hiding their problem* as the primary means of coping with their bedwetting. This was evidenced during all of the developmental stages of pre-adolescence, adolescence and young adulthood. Within the pre-adolescence years the participants believed that their problem could be fixed and they would then be able to live a normal life.

However, as they entered adolescence their bedwetting at night began to impact on all aspects of their lives including their identity and the choices they made regarding their future. As they reached young adulthood, all participants spoke of being socially isolated as a means of coping with their problem. At this stage they also came to the realization that their bedwetting may be present for the rest of their lives.

These findings reinforce that all health professionals and the community need to be provided with more information regarding this important and currently hidden health issue occurring in young males. The provision of, and access to, appropriate community resources and health services to ensure early diagnosis and support is needed to optimize the quality of life for this group of people.

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CHAPTER 1: Introduction

What is man when you come to think upon him, but a minutely set ingenious machine for turning with infinite artfulness, the red wine of Shiraz into urine? You may even ask which is the more intense craving and pleasure, to drink or to make water (Bloom, Pohl & Norgaard, 1994).

1.1 Introduction and background to the study

Internationally, there is little research reported about the “lived experience” of young adult men and women with persistent night time bedwetting and this dearth of literature provided the impetus for this qualitative research. The problem is common in the early years, with most children resolving the problem of wetting the bed by the time they reach school age. However, research conducted in Israel (Belmaker & Bleich, 1986), Scandinavia (Djurhuus, Norgaard, & Hajalmas, 1992; Hirasing, van Leerdam, Bolk-Bennink, & Janknegt, 1997), and Hong Kong (Yeung et al., 2004) has identified that in one to two per cent of otherwise healthy individuals, the problem continues through the teenage years into adulthood. As the incidence of bedwetting is higher (3:2) for males compared to females in late adolescence and early adulthood (Norgaard, et al., 1997) it was decided to focus this research on male youth. If treatment is unsuccessful, living with bedwetting may lead to ongoing physical problems, psychosocial disadvantage, social isolation and decreased quality of life for the affected person.

Two recent, large epidemiological studies have suggested that one to two per cent of young adults wet the bed, (Yeung et al., 2004; Hirasing et al., 1997). Both groups of authors have commented that this health issue is poorly publicised and that the affected person’s career, social life, psycho-social well being and personal

relationships are profoundly affected by the experience. The authors also identified that there is a scarcity of research in respect to the personal experiences of these people and the coping strategies they have used. In one of the few personal accounts that have been published, DeGraff (1992) relates that the medical tests he experienced, including a psychiatric assessment, changed his personality and that the experience of bedwetting affected his relationships and career, as well as his social and family wellbeing.

Allen and Hall (1988) have suggested that diagnostic labelling employed by the medical profession has not only led to the medicalization of life's processes, such as bedwetting, but it has also had the tendency to transform the social into the biological. The biomedical model was first devised in order to study physical disease processes, such as infections and nutritional deficits (Engel, 1977). While the biomedical model has been successfully applied to relatively straight forward health problems over a long period of time, it has had very limited success when it has been applied to complex issues, such as bedwetting, that involve the interaction between biological, psychological and social causal processes. Unfortunately, a historic lack of appreciation for the complex biopsychosocial nature of bedwetting and the lack of professional understanding of the need for comprehensive biopsychosocial assessment and management has had a negative impact on those who wet the bed and their families. Furthermore, like so many health problems that have a psychological component, adult bedwetting in particular, carries with it a social stigma that intensifies the burden placed on the individual sufferer.

More recently, the biomedical approach to the assessment and management of bedwetting has been challenged. Longstaffe, Moffatt and Whalen (2000), for example, have suggested that an important component of an efficacious intervention for children with bedwetting is follow-up and emotional support. Neveus et al, (2010), have concurred, suggesting that the general medical practitioners or nurse encourages the child to lead a normal life and reassures them that they will become dry at night, thus empowering the individual with belief in their own ability. With the introduction of clinical nurse specialists (Continence Advisors) to help people of all ages manage both day and night wetting there is a great opportunity to promote a biopsychosocial approach to care. Nurses will need to make a concerted effort to utilize their knowledge and take control of their practice within their clinical role by utilizing a truly family-centred model of care (Kendall & Tallon, 2011). This approach to the management of bedwetting in the early childhood years will provide a clear pathway for ongoing support and instil confidence in those who continue to wet the bed and their families, that effective help is available.

1.2 Need for the study

There is an urgent need in the Australian community for appropriate information about bedwetting which is a poorly understood health problem especially when it occurs in adolescents and young adults. Even general medical practitioners are often ill informed about this hidden health problem. One of the most perplexing problems to confront urologists and other health professionals working in this area of health care is the management of bedwetting in fit, healthy young adults. The majority of patients have normal bladders and normal daytime control, and why this control

should break down during sleep in some patients, but be maintained in others, remains unexplained. In the general community, most children aged five to 14 years who wet the bed are offered management and community awareness of avenues for help are well established. However, management is not successful for all children and others relapse in later childhood or adolescence. A proportion of these children will go on to wet the bed as young adults. By comparison with children, the referral processes and the avenues for helping young adults who wet the bed are poorly defined. This is despite the fact that new modalities of medical treatment may be effective.

1.3 Significance of the study

There is currently no published research that has investigated the lived experience of bedwetting in male youth. It is anticipated that this study will fill a gap in the literature in this area and assist nurses and other health professionals working with adolescents and young adults who wet the bed to gain a greater understanding of this phenomenon, therefore improving their referral and management. The findings of this study may provide evidence of the difficulties of young men involved and how they cope and manage with bed wetting. This study may encourage them to seek professional support and treatment, and to overcome their problem, and to improve their quality of life.

1.4 Purpose of the Study

The purpose of this phenomenological study is to explore and describe the lived experiences of otherwise healthy young men who wet the bed. Adult bedwetting is a hidden disorder that carries with it a damaging social stigma. There is very limited

evidence that bedwetting may lead to ongoing physical problems, psychosocial disadvantage, social isolation and decreased quality of life for the affected person.

1.5 Definitions and classifications of terms

Polite terms used to describe the passing of urine are micturition, urination, voiding, and passing water. In keeping with society's perceived distasteful nature related to the practice of passing urine and its association with the genitalia and sexual activity, a number of vulgar slang terms are also commonly used, such as peeing and pissing, and euphemistic terms, such as weeing. Bedwetting is a colloquial term that is commonly used to describe urinary incontinence or bedwetting at night. Nocturnal enuresis is a medical term for urinary incontinence at night. This and other medical terms which will be used in this thesis, are those presented by the Standardization Review Committee of the International Continence Society, (Abrams et al., 2002). The definitions presented in Table 1 below are compatible with the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health and the International Classification of Disease Version 10, (Abrams et al., 2002).

Table 1. Definitions of words associated with bedwetting

Word	Definition
Urinary incontinence	The complaint of any involuntary leakage of urine.
Enuresis	Involuntary loss of urine – if used to denote incontinence during sleep, it should always be qualified with the adjective nocturnal.
Bedwetting	In medical terms, bedwetting is the complaint of loss of urine during sleep. This term is also used interchangeably with the social term of bedwetting, which best fits this quality of life study.
Continence	Is referred to by the International Continence Society as lower urinary tract function that includes physiologically, bladder storage and urethral closure as controlled by maturation of the central nervous centre to the cortical centre of the brain.
Polyuria	The measured production of more than 2.8litres of urine in 24 hours in adults. It may be useful to look at output over shorter time frames.
Micturition and voiding	Term used to denote passing of water (urine).
Detrusor overactivity	Is incontinence due to an involuntary bladder contraction (not within the person's control to inhibit the desire to pass water).
Urodynamics investigation	Denotes measurement of the filling phase of the bladder until permission has been given to the person to pass water or void. Results of this test may disclose hidden over activity of the bladder.
Primary Nocturnal Enuresis (PNE)	Not ever having attained night time dryness (Hallgren, 1957)
Secondary Nocturnal Enuresis (SNE)	Those that had managed to have a dry periods of at least several months (Hallgren, 1957)
Mono-symptomatic, non mono-symptomatic	Based on the absence or presence of bladder dysfunction, (Butler, 2001)

The above definitions are referenced from the International standardization of terminology (ICCS), Neveus, T., von Gontard, A., Hoebeke, P., Hjalmas, K., Bauer, S., Bower, W., and Djurhus, C., (2006) In this phenomenological study it is not intended to clarify any diagnoses and therefore the researcher chose not to differentiate between the terms PNE and SNE.

1.6 Assumptions underlying the study

Whilst bedwetting is a very common problem it is often needlessly tolerated because of a certain reluctance to discuss what is often perceived as an awkward and

embarrassing subject. Health professionals are often dismissive, offering advice that children will “grow out of it”. It is only in the past decade that the subject of adult urinary incontinence has been seen as an important health issue. Even then, health services have mainly focused on the elderly and the cost of incontinence management products. One group that has escaped focus more than any other is the group of people who, despite otherwise normal development, continue to wet the bed into early adulthood. They are the adults who never ‘grow out’ of bedwetting. Reflecting on my own clinical practice over past decades, my thoughts have often been drawn to people, such as the 19 year-old university student, the 25 year-old male, and the 46 year-old bachelor, who have sought my help to try to find an “answer” to their problems of bedwetting.

The research literature about bedwetting has been primarily guided by the quantitative paradigm and the importance of objective evidence. This research focuses more on the disease itself than the lives of the people who experience it. Social, cultural and historical aspects of patients’ lives are often taken for granted, and the impact on families underestimated yet, individual psychological and social factors are critically important in determining health outcomes, as evidenced in chapter 3 – Results. Harper and Hartman (1997) capture the true essence of these sentiments when they suggest that the nurturing of hope, confidence, and positive self- esteem may make all the difference to whether a treatment works. The principal assumption underlying this study is, therefore, the belief that qualitative research that seeks to uncover the personal experience of health and illness has the potential to make an important contribution to optimising health and quality of life. Also the knowledge produced by such research, is what may inform change.

1.7 Objectives of the study

The specific objectives of the study were;

1. To explore and describe the lived experience of young men who persistently wet the bed;
2. To identify the personal psychosocial circumstances that influence these experiences; and
3. To discuss the findings within the context of current literature in the area.

1.8 Summary

Wetting the bed at night is a normal part of early development. While most children have gained complete bladder control by the time they go to primary school, small numbers of these children continue to wet the bed in later childhood and adolescence. For one to two per cent of otherwise healthy individuals the problem persists through adolescence into early adulthood. Adult bedwetting is a hidden disorder that carries with it a damaging social stigma. There is very limited evidence that bedwetting may lead to ongoing physical problems, psychosocial disadvantage, social isolation and decreased quality of life for the affected person. The purpose of this phenomenological study is to explore and describe the lived experience of otherwise healthy young men who wet the bed. It is anticipated that this study will fill a gap in the literature in this area and assist nurses and other health professionals working with people who wet the bed to gain a greater understanding of this phenomenon. It is hoped that these people will, in turn, inform general practitioners and the general public and that the referral and management of young adults who wet the bed will be greatly improved.

1.9 Organisation of the thesis

Chapter one has introduced the reader to the background literature, need, significance, purpose, and assumptions of the study. This chapter has also informed the reader of the terms used, the objectives of the study, and any limitations anticipated by the researcher. The ethics surrounding this qualitative research were outlined and the chapter concluded with a summary.

Chapter two provides a selective, critical review of the literature on bedwetting. It begins with an introduction to controlled sanitation, the history of incontinence, the social and cultural significance of continence, and the clarification of the term. After placing bedwetting in its historical, social, and cultural context, the chapter proceeds to briefly outline the epidemiology, aetiology, pathophysiology, medical treatment, and nursing management. The following sections of this chapter introduce the reader to theories relevant to bedwetting and human development and, in the absence of literature specific to bedwetting, literature about the experience of young people with a chronic condition or disability who are making the transition to adulthood.

Chapter three describes the methodology used in this study. It begins with an outline of the qualitative paradigm, phenomenology, and Giorgi's methodological approach. A review of the procedure for recruitment and the interview format, participant selection, and profile, bracketing in phenomenology research and a brief overview of how the data was analysed. The last part of the chapter considers trustworthiness, credibility and ethical issues.

Chapter four presents the findings of the study using Giorgi's method of phenomenology to describe the lived experience of male youth who have persistent bedwetting. The major theme titled "Hiding the problem" and three sub-themes were identified that together provided rich descriptions of the lived experiences of these young participants.

Chapter five presents the reader with the researcher's discussion and recommendations arising from the findings of the study. References, and the appropriate appendices, complete the thesis.

CHAPTER 2: Literature Review

2.1 Introduction and chapter overview

This chapter provides a selective review of the literature related to the lived experience of bedwetting in male youth and early adulthood. The strengths and weaknesses of prior research were reviewed and major conclusions were drawn from these studies, noting what still needs to be investigated, with a view to determining a more holistic understanding of the appropriate community treatment and management pathways essential for adolescents and young adults who currently live with persistent bedwetting.

To appreciate the significance of bedwetting for persons during this period of development it is important to understand the historical and cultural context of usual elimination practices. Like so many aspects of human behaviour, the practice of urination differs among people from different cultural backgrounds and points of time. The meaning of bedwetting is historically and culturally embedded. While not the focus of this research, it is also important to know something about the physiology and pathophysiology of urination, the prevalence of bedwetting among youth, as well as current medical treatment and nursing management.

Furthermore, as a precursor to understanding the lived experience of bedwetting as a young man it was important to review historical and contemporary theories of social and emotional development. This theoretical understanding will provide the reader with a framework on which to interpret the empirical findings of the project. This interpretation will be undertaken in chapter 5 of the thesis.

Finally, the most specific literature regarding bedwetting in male youth was reviewed in some detail. In view of the fact that experiential research about the experience of youth living with a chronic illness or disability was explored in order to highlight potential benefits and disadvantages for these young people. As this developmental period is notable for the major transition from dependence on the family of origin to an independent life, it is full of challenges. Major issues include: career development, independent living arrangements, intimate relationships, and forming social networks. This literature will form a basis on which the experience of bedwetting in male youth can be compared and contrasted.

2.2 The introduction of controlled sanitation

Sanitation and the disposal of urine and faeces did not really present a problem until the human species progressed from a hunter-gatherer type of economy to an agricultural economy about 10,000 years ago, although some 400,000 years ago human fossilized faeces were found to be deposited a considerable distance away from clearly defined living areas (Smith & Smith, 1987). Once cities and towns emerged, the disposal of human excreta became problematic, especially when it was proven to be the major contributor of death through cholera and typhoid in contaminated drinking water. According to Teresi (2002), the third millennium B.C. was the "Age of Cleanliness." Toilets and sewers were invented in several parts of the world, and circa 2800 B.C. some of the most advanced societies had lavatories built into the outer walls of houses. These were "Western-style" toilets made from bricks with wooden seats on top. They had vertical chutes, through which waste fell into street drains or cesspits. Sir Mortimer Wheeler, the director general of archaeology in India from 1944 to 1948, made the observation that the sanitary

arrangements would have been envied in many parts of the world today (as cited in Teresi, 2002). However in those days these toilets were only used by the affluent classes and most people would have squatted over old pots set into the ground. It was in 1848 when the first Public Health Act in the United Kingdom took the first steps to improving sewage systems and water supplies and the first phase of the London sewerage system opened in 1860 proving five years later that the safe disposal of sewerage did have a direct link to the cholera and typhoid epidemics people had experienced.

Attitudes towards the use of toilets are determined by our Western European culture and the unattractiveness of the topic is a possible reason for the lack of research into continence and incontinence (Smith & Smith, 1987). Of great interest are the various euphemisms used world- wide to express the use of the toilet; lavatory, loo, bathroom, WC (water closet), CR (comfort room), dunny (Australian for outhouse), netty (common word used in North East London) and privy used in the North of England (and referring to private or “privy council”) also used in North America. Juuti and Wallenius (2005), in a research paper on toilets in Finland, suggest that toilets have not attracted interest from artists, philosophers or folklorists simply as they are not a meeting place, unlike the advent of the well, and that in many countries talking about toilets and or bodily functions is a taboo.

This historical overview underscores the way controlled sanitation has evolved in Western societies. It is clear that practices have changed markedly from prehistoric to modern times. It is likely that the means of elimination will change again with

future technological advances. The historical, social and cultural significance of incontinence will be discussed in the following section.

2.3 Historical, social and cultural significance of continence / incontinence

In the 1800's the first written reference to urinary incontinence was found in a detailed case history in the Edwin Smith Surgical Papyrus, dating from the seventeenth century BC, cited in (Bloom, Pohl, & Norgaard, 1994). This detailed case history concerned a man with quadriplegia following a cervical vertebrae injury who had over-flow urinary incontinence, and described his "urine dribbles" as an "ailment not to be treated" (Bloom et al., 1994, p.285). According to Bloom et al. (1994) there were no other references to urinary incontinence and the subject was rarely mentioned in the ancient literature. Although in 1544, Ketham's "Fasciculus Medicine", a General Practitioner's text, and one of the first medical books produced by printing press, explained a treatment for bedwetting (cited in Milne & Moore, 2003). It is very likely that incontinence was not seen as a problem before the advent of the water closet style of toilet in Victorian Britain because standards of hygiene were vastly different from those of today. In societies where people were used to urinating and defecating in the presence of other people either in their homes or in the street it would have been far less noticeable.

The importance attached to bladder and bowel control is as old as the human race (Getcliffe & Dolman, 2007). Adults in all societies regard faeces as offensive however this is not universally true of urine. It is important to understand the taboos surrounding toileting because they influence the attitudes of the general public and health professionals (Getcliffe & Dolman, 2007). In some countries public toilets are

separate for men from women, for reasons of cultural modesty. In many countries, the more developed and crowded the physical environment, the more urinating in public is objected. For example, in Australia it may be considered appropriate to squat behind a tree if travelling in the countryside, whereas it would be considered unacceptable in a town or city. Both men and women in Africa, Vietnam and Laos, for example, urinate out doors because of lack of facilities. In Cambodia it is usual to urinate next to a bush or at the side of a building, with women wrapping a cloth around them, to maintain their dignity. In other societies and among the higher social classes even mentioning the requirement to pass urine is seen as a social transgression, despite the human universal need (Juuti & Wallenius. 2005).

In modern times, incontinence has become a significant issue particularly in Western societies where standards of personal hygiene have become very high. It is only within a generation or two that people have begun to shower every day and adorn themselves in clean clothes. Even the middle-aged today will remember a time when most people bathed and changed their clothing once or twice a week. Many of the very elderly will remember a time when people would urinate at night in a pot kept under the bed. The smell of urine would permeate the bedroom air and mask the smell of urine left from bedwetting (Smith & Smith, 1987).

2.4 Anatomy and physiology of continence

The anatomy and function of continence comprises the upper and lower urinary tract, made up of two kidneys, two ureters, a bladder and a urethra. Physiologically the bladder and urethra comprise the lower urinary tract and are innervated by the sympathetic nerve fibres from the spinal cord and the parasympathetic fibres from

the sacral spinal cord. There remains much confusion concerning passing urine and the basis of the changes in this process. At the supra-spinal level, however, passing urine is fundamentally a spinobulbo-spinal reflex facilitated and inhibited by the higher brain centres such as the pontine centre and subject to voluntary facilitation physiologically. There are two discrete phases in the healthy individual . The first phase involves coordination between the central, autonomic, and somatic nervous system that is regulated by the brain centres such as the pontine micturition centre, periaqueductal grey and the cerebral cortex (Huether & McCance, 2000). The second phase which is usually acquired at the age of two to three years, is a conscious process whereby sensory fibres from the bladder and the urethra send a signal to the brain to tell the individual that the bladder requires emptying (Getcliffe & Dolman, 2007). Continence is described by the International Continence Society (ICS) as a lower urinary tract function that includes the storage of urine in the bladder and urethral closure that, upon maturation, is controlled by the central nervous system (CNS) through a cortical centre in the brain (Neveus, 2009). According to Getcliffe and Dolman (2007) continence occurs when a person acquires the ability to store urine in the bladder and to excrete voluntarily where and when it is socially appropriate. Continence is dependent on the intimate relationship between several factors, including: physiological maturation of the CNS, an appropriate bladder capacity; the recognition of the sensation to pass urine; self awareness; and being able to manage clothing appropriately, the average child first recognising bladder signals at two years of age (Getcliffe & Dolman, 2007). Maturation of the CNS is the first important factor to consider when discussing incontinence in children, however it is not an issue in the adult population, where changes in the CNS are very different in that they are more disease or trauma related (Neveus et al., 2006). The literature

suggests that children are taught to be proud of their toileting, aiming for day control approximately at three years of age and night bladder control at five years of age (Getcliffe & Dolman, 2007).

2.5 Pathophysiology and aetiology of bedwetting

Physiologically, the chronological age expectation for night bladder control is five years (Norton, 1996), which for Australian children coincides with the initial independent social step into formal education. After this age, children who have failed to achieve central nervous system control over both bladder contractions and bladder function are deemed to have developmental delay (Koff, 1995). Bedwetting is considered multifaceted, and according to Neveus (2009, p.199), there is still an “irritating lack of proven effective therapies”. Butler and Holland (2000), and Butler (2004) commented on the heterogeneity of bedwetting suggesting no one causative factor. (Neveus et al., 2007) suggested that although some advances have been made in investigating the aetiology of this problem, “modern research has established three major pathogenetic mechanisms as crucial, including nocturnal polyuria (excessive urine production), detrusor overactivity (unstable bladder contractions), and an increased arousal threshold” (Neveus et al., 2010, p. 442). Furthermore, Shreeram, He, Kalaydjian, Brothers and Merikanga (2009) found a close correlation between bedwetting and attention-deficit/hyperactivity disorder (ADHD), in a sample of eight to 11 year old school children, recommending the importance of specifically enquiring about symptoms of bed wetting and its effects on the emotional health of the child and the family. With uncertainty about many aspects of the pathogenesis of bedwetting it is appropriate to outline evidence for the least controversial risk

factors: heredity; polyuria; sleep disturbance; and behavioural and psychosocial factors.

2.5.1 Heredity

Bedwetting is often inherited, with past research showing evidence for a strong genetic disposition to bedwetting, the risk being 75 per cent if both parents had been enuretic as a child and 45 per cent if only one parent (Butler, 2004; Lottman & Alova, 2007). Current research however suggests that genotype and phenotype are not closely linked, due to the multifactorial nature of the diagnosis, (Schaumburg et al., 2008). Factors that have been found to be associated with delayed acquisition of nocturnal bladder control include: low birth weight; shorter stature; delayed motor development, especially fine motor skills; delayed speech and language development; and poor visuo-motor and spatial perception (Jarvelin, 1989; Jarvelin et al., 1991; Getcliffe & Dolman, 2007). Field, Austin, An, Yan, and DeBaun (2008) found a high correlation between enuresis and sickle cell anaemia between the ages of six and eight years and that it continued to be common in young adults ages 18-20 years. Early studies on twins have shown that the genetic formulation seems more apparent in boys than in girls (Butler, 2004).

2.5.2 Polyuria

Polyuria (excessive urine production) has been cited in papers (Neveus, 2009; Butler & Holland, 2000) as a major physiological factor contributing to bedwetting. The lack of vasopressin (AVP) produced in the hypothalamus that would otherwise normally result in a reduction of urine volume during sleep, has been discussed as a reason that most children who are not bed wetters tend to sleep through the night

without being wet. This excessive volume of urine may, cause an unstable contraction (detrusor overactivity) and it is still not known the true pathogenetic significance of nocturnal polyuria and/or detrusor overactivity. With the treatment of specific medications for this problem an estimate of 30 per cent of children with bedwetting are full responders and 40 per cent have partial response – in the studies of urine production there are conflicting results. Another variable recently discussed by the same author has been the co-existence in a third of children with bedwetting of detrusor overactivity and constipation (Neveus, 2009).

2.5.3 Sleep disturbances

It is common for parents to believe that their child wets the bed because he/she is a deep sleeper (Butler, 2004). Recent in-depth research by Yeung and colleagues in Hong Kong (cited in Neveus, 2009) found that bedwetting children had more superficial sleep (although they did not wake up before voiding) than a control group. It was thus hypothesised “that the signals from the overactive/or over distended bladder continuously disturb the sleep, whereby arousal thresholds were paradoxically increased in order to preserve sleep integrity” (Neveus, 2009, p. 200). Of further note concerning sleep deprivation is the finding that people who wet the bed are reported to experience more difficulty in falling asleep and wake more often during the night or in the early morning” (Yueng et al., 2008). It is generally agreed that there is still considerable research required to understand the relationship between the micturition reflex and sleep and arousal mechanisms (Neveus, 2009).

2.5.4. Behavioural and psychosocial factors

The development of continence, which involves the child understanding social expectations, is influenced by family attitudes and expectations, as well as psychosocial factors, such as parent child relationships, parenting skills, and the family's experience of stressful life-events (Getcliffe & Dolman, 2007). For example, Liu, Sun, Uchiyama, Li, and Okawa (2000) found that breastfeeding and family stability were protective for bedwetting, while a maternal age under 20 years and a history of heavy smoking were risk factors. More recent studies have disputed the association between bedwetting and psychological/psychiatric problems, and have discredited the psychoanalytical explanatory models used to guide the research. It is now thought that the association between behaviour and bedwetting is mostly due to low self-esteem (Del Gado et al., 2005).

2.6 Prevalence of incontinence and bedwetting

Bedwetting has been described as the most prevalent and chronic of all childhood developmental problems, with an estimated three quarters of a million children in Great Britain and some five to seven million children over the age of seven years in the United States experiencing bedwetting to some degree (Butler 2004, Butler, Goulding & Northstone, 2005). The results of epidemiological studies confirm that 15-20 per cent of five-year-olds, five per cent of ten-year-olds, and two to three per cent of adolescents and adults wet the bed at least once a month (Norgaard et al., 1997). Neveus (2009) suggests there are no major cultural or racial differences in the prevalence of bedwetting. With regard to adult bedwetting, Belmaker and Bleich (1986) estimated the prevalence of bedwetting in men aged 18 – 20 years in the Israel Defense Force as one to three per cent. In Scandinavia (Djurhuus, Norgaard, &

Hajalmas, 1992; Hirasing et al., 1997), and Hong Kong (Yeung et al., 2004) the prevalence of bedwetting in otherwise healthy adults has been estimated at between one and two per cent.

A more recent study suggests that three per cent of all men and two per cent of women under the age of 40 years admitted to having problems with bladder control whilst asleep (Yueng et al., 2008). One quarter of the sufferers experienced the problem every night, while around half were wet up to three nights a week. This frequency of wetting indicates severe symptoms. This study dispels the myth that the condition improves as individuals become older and it indicates that bedwetting in adults is very unlikely to cease spontaneously (Yueng et al., 2008).

2.7 Current medical treatment options

The basis of medical treatment may be broadly categorised as psychological or pharmacological, or a combination of both (Butler, 2004). Norgaard, (2006) stressed the fact that the balance between nocturnal urine output volume and bladder capacity is important along with the persons' response to waken. Current literature suggests that the first approach to treatment given a motivated person, and a supportive family, is the bell and mat alarm system. This system comprises a mat, covered by a bed sheet on which the person lays. This mat with very low voltage wiring is attached to an alarm which will sound should the person pass urine. This loud alarm stimulates the upper cortical centre in the brain, awakening the person to respond to the need to urinate. This program has shown positive results in up to two-thirds of children becoming dry at night (Neild & Kamat, 2004; Lottman & Alovera, 2007). It is presumed that success is due to the effect of conditioning on arousal Butler et al.,

2007, cited in (Neveus et al., 2010). The principle line of pharmacological treatment for the intransigent child, those who may have regressed with the bell and mat alarm system, and the young adult with persistent bedwetting is that of an antidiuretic vasopressin analogue, that is available as a tablet and a rapidly melting oral medication. This medication, acts as a potent antidiuretic to concentrate the urine and minimise urine production and subsequently the volume/ pressure within the bladder (Neveus et al., 2010). The literature suggests many people have a safe and positive response with the use of this medication (Neveus, et al., 2010; Lottmann & Alovera, 2008). However, the medication is not suitable or effective for everyone and consequently there is much more to the management of bedwetting than simply taking a pill. Nurses play a pivotal role in assessment and the provision of education and emotional support.

2.8 Nursing management

Currently in Western Australia and most Australian States, the assessment and management of incontinence is undertaken by nurses with a Post-graduate Certificate in Continence. Nurses, whether in a family practice, school health, or urological practice, are in an ideal position to manage children and adults who wet the bed. Nurse led clinics have been established in various private and state tertiary health institutions. The public may self-refer to these clinics and, owing to the severe social stigma associated with the disorder, few adults readily admit to bedwetting or seek treatment (Vandersteen & Husmann, 1999). Furthermore, while programmes for helping children are well established, the avenues for helping young adults with bedwetting are poorly defined, despite the fact that new modalities of treatment may be very effective (Neveus, 2009). The issue of social stigma associated with

bedwetting will be discussed in more detail, page 59.. In a study by Sakakibara et al. (2007), it was found that almost 50 per cent of families self-treated their child by waking them at night and/or restricting fluid intake to prevent the child wetting the bed, and 45 per cent waited for the child to grow out of the problem, thus accentuating the historical role of families particularly the mother, in health care. Most doctors consulted for bedwetting adopt a “wait and see” approach and lack motivation to take care of bedwetting patients who required time and an ongoing regular treatment programme (Lottman & Alova, 2007). In general, the social environment provided for young people could be greatly enhanced if nurses working in this area had detailed knowledge and understanding of the common developmental issues faced by this age group. A consideration of the impact that bedwetting has on the psychological and social functioning is especially important, given the very high rates of mental health problems (Wynaden, 2010). Furthermore, with increased understanding, attention might be drawn to the issue of bedwetting, itself, so as to encourage young people to come forward for help.

Current literature discusses the major responsibility experienced by the family in respect to bedwetting (Sakakibara et al., 2007). From the nurse-led clinic perspective, it is agreed that good management begins with the development of a therapeutic relationship with the families (Kendall & Tallon, 2011), taking time to explain what is known, epidemiologically and aetiologically about bedwetting and the role that conservative practical interventions play in the initial approach in such management (Klein, 2001). However, this approach which is taken by many nurses is steeped in history and framed by the medical model of care. The medical model has promoted the idea that health professionals know best and that to improve or manage their

disease, patients have an obligation to comply with the information provided.

Furthermore, the health care system in Australia is designed to provide acute care based on symptoms, and is poorly configured to treat chronic conditions, such as diabetes (Funnell & Anderson, 2004) or bedwetting. In recent times, Lau (2002) has suggested a patient-centred approach where health care providers surrender control and involve patients in making care decisions, allowing empowerment to take place. The empowerment model promotes the acknowledgement by health professionals that the patient provides valuable information and discussion rather than confrontation, thus limiting judgements made about the patient's behaviour. The model also provides an avenue for mutual respect where there is valuing of human life and the foundations for a good clinician-patient relationship (Lau, 2002).

Empowerment from the patient's perspective was nicely summed up by Weiss (2006, p.116) when he suggested that it acknowledges the way in which behavioural changes occur by casting patients as the central figure in the design and implementation of their care plans. Murphy (2008, p. 697) in a paper discussing an agenda for health promotion, claimed that much of society focuses on health and health care by referring to knowledge of medical technology and bioethical principles, however this approach omits the social conditions associated with many health outcomes.

Nurses who conduct continence clinics for children who wet the bed have for some time adopted a family-centred care (FCC) approach. According to FCC it is the responsibility of the child to manage his/her own program, with family support. The child is responsible for any wet bedding during the night, is required to change bedding, reset the alarm bell, and make telephone contact with the clinic to report

progress. While the successful application of behaviour modification techniques to the management of bedwetting is not questionable, it is questionable if this practice truly is FCC. Kendall and Tallon (2011) suggest that there is much more to FCC than simply allowing patients and their families to perform routine self-care activities. FCC identifies the importance of the family as a context for health and development and the importance of health professionals considering the psychosocial situation of the family in their plan for care. Families often need physical and emotional support to help them care for their child appropriately (Kendall & Tallon, 2011). Following psychosocial assessment, the practice of FCC involves the development of a therapeutic relationship and the giving of appropriate support so as to help the family take control of their situation.

What is suggested by Kendall and Tallon (2011) is that nurses need to take control of their own time so as to be able to practice within their own knowledge-base and have voice regarding the constant pressure from administrators to cut costs. Clinic nurses need to be focused on individualising history taking and assessment to ensure that the approach is not one of “one model fits all”. There are compelling reasons to empower nurses, themselves, in order to create a workplace that has the requisite structures to promote empowerment (Manojlovich, 2007).

2.9 Theories of human development relevant to bedwetting

As mentioned in the introduction, it was important to review historical and contemporary theories of social and emotional development because this theoretical understanding provides the reader with scaffolding on which to interpret the empirical findings of the project. The review begins with the “grand”

psychoanalytical, behavioural and cognitive theories of development and concludes with the “emergent” socio-cultural and epigenetic theories (Berger, 2008).

Freud’s psychoanalytic approach emphasised four stages of development – the “oral stage” in infancy, the “anal stage” in early childhood, the “phallic stage” in pre-school, leading to a life-long stage referred to as the latency or “genital stage” (Berger, 2008). Freud constructed this multi-faceted psychosexual theory around the sexual urges experienced by humans believing that a parental reaction to a child’s behaviour has a lasting impact on their personality. In relating psychoanalytic theory to bedwetting, Butler (2004) states that parents are typically concerned about the impact of bedwetting on their child and that those feeling under stress often become intolerant, and they attribute bedwetting to factors the child can control, leading to feelings of annoyance and the punishment of the child. This parental intolerance can lead, in turn, to dropout or early withdrawal from treatments and a dependency of the child on the parent to guide the way for treatment. This parental intolerance maybe related to the (Freud’s) psychosexual stages to bedwetting and the child’s development (one to three years). This is a period in the early developmental years that focuses on toilet training as one of the most important social skills to be acquired in society.

This Freudian interpretation is supported by another of the grand theorists, Erikson, whose psychosocial theory, discusses the child becoming self-sufficient in toddlerhood and the preschool years in many activities including toileting, feeding and walking (Berger, 2008). Those who are successful gain “autonomy”, while those who are not have “shame and doubt”. Erikson’s emphasis was on family and culture

not sexual urges, which would continue throughout life. However, both theorists, most critically, identified adult outcomes as having their genesis in early childhood and this proposition fits into the more recent bioecological theory (Williams, Holmbeck, & Greenley, 2002).

A further grand theory is the cognitive approach, developed by Piaget (1896-1980). Piaget conceived of four periods of cognitive development, not unlike Freud's four stages, referring to them as the sensorimotor, preoperational, concrete operational, and formal operational stages. He believed that thought processes are powerful influences on human behaviour and development.

Despite cognition being central to Piaget's theoretical framework, describing how children acquire knowledge, it also touches on social and emotional development (Avan & Kirkwood, 2010). A follower of Piaget, Kohlberg (cited in Avan, & Kirkwood, 2009), considers only one domain of child development, that of socialisation by which the child learns to conform to the ethical expectations of their culture with the reasoning of good boy/girl obedience and punishment. This theory supports the treatment modality of the bell and mat alarm in which children are rewarded once "dry". The behavioural theorists disagreed with psycho-analytical and cognitive theory stating that all behaviour is learned step by step and becomes a habit. Of note is that behaviourism looks only at what a person may do, not what they think, feel or imagine (Berger, 2008).

Pavlov, a physiologist and Nobel Prize winner for his work with the digestive system, demonstrated by working with dogs the behavioural theory referred to as

“classical conditioning” (Berger, 2008). By pairing a neutral stimulus (the ringing of a bell) with a meaningful stimulus (the smell of food) Pavlov demonstrated that the animal’s behaviour could be changed. The “bell and mat” alarm system used in the management of bedwetting is based on classical conditioning (Neveus et al., 2010). The child pairs the ringing of the bell (neutral stimulus) with the act of urination (meaningful stimulus) and he/she eventually stops urinating when the bell sounds (change in behaviour). However, the bell and mat intervention also includes a component whereby the child is given a reward of their choice for not wetting the bed. The act of rewarding desirable behaviour also has its basis in behavioural theory, that of Skinner’s “operant conditioning”. In keeping with behavioural theory, the reward must be meaningful for the child (Monda & Husmann, 1991; Nield et al., 2004; Lottman & Alovera 2007; Neveus et al., 2010). If the response is useful or pleasurable, the person is likely to repeat the behaviour, and if painful or without pleasure it is unlikely to be repeated. With the use of the bell and mat alarm system, special treats are given as well as verbal affirmations, which empower the child and give a sense of owning “the problem” (and the asserting autonomy as discussed by Erikson). Although different educational and verbal treatment information is not fully discussed in the literature, what is discussed is the type of parental/guardian support, and that the child must be responsible for managing the alarm when it sounds, replacing bedding and resetting the alarm (Neveus et al., 2006).

Social learning theory, which has its roots in behaviourism, was developed by Bandura (Berger, 2008). The central tenet of this theory is that children observe and learn from others as social beings. Having observed others, children “model” or copy the observed behaviour in a process similar to classical conditioning. When the child

is praised or rewarded in some other way for the behaviour, it is repeated as in operant conditioning (Berger, 2008). Praise and reward can play a major part in the treatment of bedwetting and may be used by parents as one of the first incentives to encourage dry nights. Social learning theory, or context-based theory, as described by Avan and Kirkwood (2010), implies that children are not only the product of their social environment, but have the potential to influence and produce this environment. Relating this developmental theory to bedwetting, the social variable confronting the child/adolescent, is bedwetting and as toileting is a learnt behaviour, the child is more likely to respond to treatment guidance if it results in an outcome they value, such as a dry bed.

When considering the previously discussed “grand” theories it is interesting to note that their focus was the cognitive, emotional and behavioural development of the individual child in isolation, whereas in socio-cultural theory human development is seen to result from interaction between the person and their surrounding social environment (Maggi, Irwin, Siddiqi & Hertzman, 2010). The most recent conceptualisation of human development acknowledges the importance of understanding processes at multiple levels from the molecular to the social, political, and economic. This contemporary model takes the view that no single theory can explain human development and that collectively all of the existing theories in psychology help to explain aspects of development as do theories that come from other disciplines – biology, history, economics, sociology, genetics and anthropology (Jessor, 1993). Furthermore, developmental behavioural science now reaches beyond the traditional boundaries of psychology to encompass the concerns of all disciplines to address the social environment of human action (See Figure 1) (Jessor, 1993).

Figure1. Ecological model attributed to Bronfenbrenner

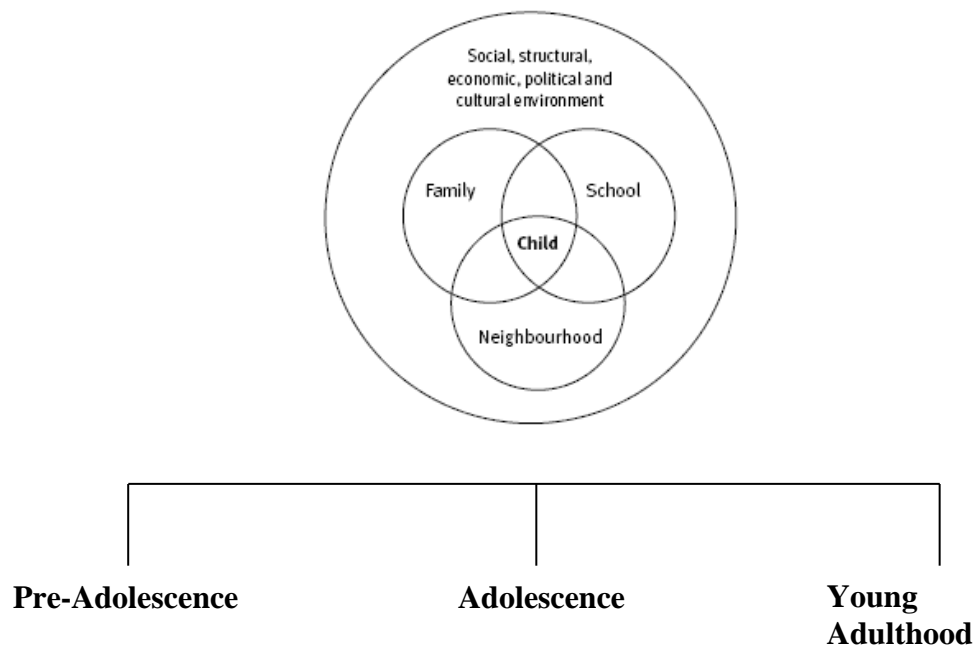


Figure 1 shows that children and people generally, grow and develop within a series of social environments. The most prominent context in the earliest years of life is the family. Later the school plays an important role. While the neighbourhood features in all periods of development, it begins to feature more in preadolescence as children become more involved with their peers. In late adolescence and young adulthood, school is replaced by tertiary education and work and there is a transition away from the family of birth. Social, cultural, political, and economic factors form the distal environment. These environmental factors also play an important role in health and development over the life-course.

These ideas and those of many contemporary developmentalists have been heavily influenced by the ecological model of human development first introduced by Bronfenbrenner in the 1970's (Jessor, 1993). Bronfenbrenner has challenged the shortcomings of heritability, suggesting that there are many complex factors influencing differences in developmental outcomes when children are growing up in

the same environment. Furthermore, the bioecological model, a later version of the original ecological model, suggests that there are systemic variations in psychological and biological processes and the characteristics of the environment in which behaviour occurs. The model emphasises the interplay between these characteristics at all levels (Bronfenbrenner & Ceci 1994).

Key developmental tasks of adolescence include: the formation of a stable identity; growing confidence or self-efficacy; and the establishment of body image and self-esteem generally. Successful development across the life-course is reflected in good mental health. Good mental health in adolescence is evident in engagement in work or study, achievement in sport and hobbies, a wide group of friends, close friends, intimate friend(s), reasonable relationships with parents, and limited risk-taking behaviour, including alcohol and substance use (Jessor, 1993). Due to complex physiological changes associated with puberty and brain growth, and the likelihood that many are not successful either at school or with friends, mental health problems, especially anxiety and depression, are very common in later adolescence and young adulthood (Andersen & Teicher, 2008). In Australia, by the time a young person reaches 24 years of age there is a 27 per cent chance they will have experienced a mental health problem for which they have sought assistance (McLennan, 1997). Once institutionalised, most patients with more obvious mental health symptoms are now being channelled into mainstream community services (Wynaden, 2010).

In later adolescence, the social environment is primarily made up of parents, teachers, peer groups and a wider culture (Leather, 2009). While there may be confrontation within the family during this time, relationships are often mutual and

reciprocal, as with peers (Masche, 2008). This period of young adulthood is characterised by multiple transitions which include peer-group identity, career choice, independence, parent-child relationships, intimacy, choosing a partner and the overall development of autonomy and emerging individualism. In a recent longitudinal study by Seiffge-Krenke (2009), the importance of earlier parenting behaviour on outcomes in emerging adulthood was demonstrated, and also the importance of parents reducing their level of support, thus allowing young adults autonomy. When considering the consequences of bedwetting, which falls outside what is considered normal for adolescent development, it is important to appreciate the individual aspects of this particular stage.

2.10 Night time bedwetting in male youth

To date, there is no published literature regarding the experience of bedwetting in male youth. There is, however, limited evidence that the experience of bedwetting is difficult for older adults. In an earlier qualitative study, Hindmarsh and Bryne (1980) found that adults suffering from bedwetting generally perceived their problem as one to be dealt with personally, in private, rather than as a proper target for medical intervention. The hidden nature of bedwetting was found to be due to embarrassment about the problem, a subsequent reluctance to seek help, and ignorance of the help available. A more recent study found that 50 per cent of participants, men and women aged between 25-34 years, had never consulted a care provider even though 30 per cent believed persistent bedwetting was treatable (Hirasing et al., 1997).

There are a wide range of factors that affect people's health seeking practice, such as family characteristics, cultural background, the social environment, poverty, and

disadvantage (Wang et al., 2007). Physiological, psychological and social maturity and independence are intermingled, and when a chronic health problem, such as persistent bedwetting is present there are additional challenges for the individual and for their family. Adults who wet the bed are subjected to scorn and ridicule in many cultures. Adult bedwetting is a stigmatised condition (Getcliffe & Dolman, 2007). It is rare for young adult sufferers in Western countries to present for treatment. The general association with bedwetting with young children places further pressure on the young adult sufferer. Often driven by their partner to seek help, they present with a feeling of shame and embarrassment (Ketcher, 2000). When reflecting on the historical, social and cultural significance of incontinence this is not hard to understand. There is an absolute expectation within Western society that bladder control at night will be attained by six years of age. The cultural and societal taboos surrounding toileting have a major influence on the attitudes of the general public and health professionals (Getcliffe & Dolman, 2007). The decision to seek help, verbalise a health problem and commit to a plan for management are all obstacles which must be overcome prior to successful treatment for this age group (Coleman, Hendry & Kloep, 2007).

As a basis of comparison, the remainder of this section briefly reviews literature regarding the transition from adolescence to adulthood for people with a chronic illness or disability. An understanding of how chronic illness and disability interface with development during adolescents and young adulthood may provide valuable insights into the lived experience of bedwetting in male youth. It is possible that the experiences of bedwetting youth are similar to those who have, what are generally thought to be a more serious problem. And yet, as Leiter and Waugh (2009, p. 520)

have suggested, youth with disabilities are almost invisible within the existing body of general social science scholarship about the transition to adulthood. This issue, which is important in its own right and an appropriate subject for nursing research, will not be discussed further here.

Most recent literature suggests that society has moved forward in its recognition of the need to replace many of the myths and false expectations surrounding young people with a chronic disease or disability with evidence-based knowledge from both qualitative and quantitative studies. However, the evidence shows that there are still many challenges associated with chronic health problems and disabilities, none more obvious than the effect that “being different” may have on mental health (Weisz & Hawley, 2002). And it remains that health care systems in Western countries are designed to deliver symptom and acute care intervention, while those with chronic health problems are primarily expected to comply with a prescribed regimen, often with a “do as I say” approach by the health professional. There is little recognition given to the broader context of the person’s life, such as their social and emotional health and the status of the family dynamics. Very little addresses the patient’s priorities, resources, culture and lifestyle (Funnell & Anderson, 2004). The remainder of this section outlines the issues of career development, independent living, and intimate relationships that are known to be more difficult than usual for young people with a chronic illness or disability.

2.10.1 Career development

Many young people who have chronic illness or disability have reduced access to employment opportunities (Leiter & Waugh, 2009). Some adolescent will not reach

adulthood with the same academic and/or social skills as their counterparts (Williams et al., 2002). Those who are most disadvantaged may have a physical or cognitive developmental delay which compromises their ability to problem-solve, and comply with management. However, there is growing recognition that youth with a chronic illness or disability if equipped with self-determining skills, attitudes and opportunities, increase their prospects of accomplishing personal meaningful outcomes during high school and throughout adulthood (Carter et al., 2010). This self-determination will consequently lead to life-long opportunities inclusive of career and income. Two factors that may help the chronically ill or disabled adolescent experience greater opportunities are attending regular schooling and taking part in general rather than special classes.

2.10.2 Independent living arrangements

Changing social contexts have contributed to the shift in age at which most young adults now leave home (Pitman, Herbert, Land & O'Neill, 2003). Fifty per cent of young adults are now living with their parents until they reach 25 years of age (Pitman et al., 2003). All youth in striving for independence are affected by the constraints of economic and residential changes, with norms passed down from one generation to another (Leiter & Waugh, 2009). Constantly changing is the context in which the adolescent chooses to remain at home. These social and contextual factors in turn reveal the key role that families often play in providing a safety net for young adults. Chisholm (1999, as cited in Seiffge-Krenke, 2009), suggests young adults continue to rely on their parents for support and tend not to enlarge their peer support compared to age-related mates. This is more likely to apply to the young adult with a chronic disease or disability, but there are variations according to culture, gender,

social class and level of education. (Seiffge-Krenke, 2009). What is changing for young adults with disabilities are the types of living arrangements now available. While many young people with a disability would have gone into residential care just a few years ago, they are now more likely to have a choice of remaining within the family environment with support, living in semi-autonomous abodes, or in autonomous households, thus increasing the feeling of independence so often central to this group in society.

2.10.3 Intimate relationships

Adolescents and young adults who appear to be physically different from their peers or have a pronounced disability (severe acne, short in stature, cerebral palsy) are more likely to have problems of body- image resulting in altered sexual attitudes or behaviour, intimacy in relationships, self worth, and self esteem, (Weisz & Hawley, 2002). However, a recent Brazilian study found that a group of adolescence with Downs Syndrome presented with “normal development in the exercise concerning their sexuality”, and they were satisfied with their body image with future perspectives of finding a partner, and getting married and having children (Bononi et al., 2009, p. 319). Having said that, what was notable were the difficulties experienced by this group in their autonomy. They often required careful interventions to assist their social interactions.

From this overview of the literature it can be concluded that many young adults with a chronic illness or disability who are attempting to understand and become integrated into the society around them, experience considerable anxiety when they believe themselves to be very different from their peers. As a result of this, the young

adult is likely to face serious obstacles in these transitional years (Coleman et al., 2007).

2.11 Summary

One of the most frequently occurring health problems in childhood, bedwetting sometimes persists into young adulthood. Bedwetting in young adults has become stigmatised and it has been largely ignored by health professionals and the general public.

The bedwetting literature has concentrated primarily on the epidemiology, aetiology pathophysiology, and medical treatment of the condition, rather than the person who experiences bedwetting and their social context. The history of controlled sanitation has outlined that attitudes towards the use of toilets are determined by Western European culture. The unattractiveness of the topic is the possible reason for the lack of recognition of bedwetting as a health problem.

It is evident in the literature that the management of bedwetting has been, and continues to be, embedded in the biomedical treatment model. Nurses need to practice within their own knowledge, and individualise history taking and assessments to ensure that the approach is not one of “one model fits all”. A consideration of the impact that bedwetting in early adulthood might have on emotional and social functioning is especially important given the nature of developmental tasks, such as the transition to independent living and the formation of intimate relationships, and very high rates of mental health problems, particularly depression in people living with a chronic illness (Wynaden, 2010). Furthermore,

with increased understanding, attention might be drawn to the issue of bedwetting, itself, so as to encourage young people to come forward for help.

CHAPTER 3: Methodology

3.1 Introduction

Chapter three of this thesis describes the methodology, research design, sampling strategy and the interview process used in this study. The chapter will begin with an overview of the qualitative research paradigm of phenomenology followed by a description of Giorgi's method of phenomenology which was chosen for this study. Finally, issues related to trustworthiness, credibility and ethical issues are presented.

Today there is a rich array of research methods to guide researchers in their pursuit of answers to their enquiries on a range of issues (Roberts & Taylor, 2002). Broadly speaking these approaches are described as quantitative or qualitative research methods. Researchers tend to perceive quantitative methodologies in the logical positivist tradition but increasingly they are also collecting and analysing data via qualitative methods. Qualitative research places emphasis upon individual aspects of human experiences and captures that context (Polit & Beck, 2006). The choice of Giorgi's method appropriate to this study is more fully described in paragraphs 3.2 and 3.3.

3.2 The qualitative paradigm

All qualitative research methods have similarities and differences. Polit and Beck (2010) described qualitative research as a naturalistic paradigm that allows the researcher to interact with participants and the findings are the creation of that interactive process. The findings are not a fixed entity but rather a composite of multiple constructions of reality. Qualitative research provides descriptions of the

phenomena under study that are rich and expansive and illuminate what it means to be a person in a particular situation or experience (Schneider, Whitehead, Elliott, Lobiondo-Wood & Harper, 2007). Qualitative methods are especially useful for exploring the full nature of a poorly understood or conceptualized phenomenon (Harper & Hartman 1997; Polit & Beck 2010). From ontological and epistemological perspectives phenomenology was identified to be the most suitable method for this study because the researcher was interested in understanding participants' lived experiences of having bedwetting that had not previously been reported in the literature.

3.3 Phenomenology

Phenomenology as a research method encompasses many different research approaches (Finlay, 2009). While the roots of phenomenology are traced back to ancient Greek philosophy it was Edmund Husserl (1900-1970), a German philosopher who is credited as the founder of the twentieth century phenomenological movement, and saw it as a radically new way of doing philosophy. The formation of the school of phenomenology was an important move forward in science and signified a shift in focus from the physical nature, cause and effect analyses, and the impersonal nature of quantitative research methods (Giorgio, 1985). However, Edmund Husserl was not against quantitative research, and he began his career as a mathematician and logician. With no fear of quantitative research methods he believed that the focus on human beings and their world was extremely important (Giorgio, 2008). Rooted in the philosophical tradition phenomenology research asks questions such as: what is it like to be or have a certain

experience? What do people experience in regard to a particular phenomenon, and how they describe (subjective) those experiences (Morse, 1998; Polit & Beck 2010).

The research goal of phenomenology is to describe fully the lived experience of the individual or group being researched. Roberts and Taylor (2002) claimed that phenomenology “concerns itself with the study of things within human existence, because it acknowledges and values the meanings people ascribe to their own existence” (p.319). Phenomenology is an especially useful approach in research when a particular situation or experience has been poorly defined or conceptualized. Topics of interest for those conducting phenomenological research are those that are fundamental to life experiences of humans, for example, quality of life issues. Phenomenology accepts experience as it exists in the consciousness of the individual (Morse, 1998). The goal is to provide an accurate description of the phenomena being studied and it is both a philosophy and a research method.

Husserl desired to integrate the world of science alongside the real “life-world” of people, from which he developed one of the two main schools of phenomenology, called descriptive phenomenology which describe experiences as they are lived in phenomenological terms for study participants. (Schneider et al., 2007). The descriptive phenomenological approach insists on the careful description of ordinary conscious experience of everyday life as experienced by the person, and understanding and defining the phenomenon. Heidegger, a student of Husserl, believed that the understanding of the person could not occur in isolation from the person’s world. For Heidegger, the phenomenological methodology was

ontological in that the subject can understand their existence and therefore, the nature and the meaning of “being”. Unlike Husserl, Heidegger argued that hermeneutics (“understanding”) was a basic characteristic of the human existence and in this he fashioned the second school now referred to as interpretive or hermeneutics phenomenology. He described the research approach as entering another’s world and discovering practical wisdom, possibilities, and understandings found there (Schneider et al., 2007). Furthermore both Husserl and Heidegger agree that the focus of philosophy has to be consciousness and human existence and towards human beings and their worlds (Giorgi, 2005). In the present study Husserlian phenomenology was chosen over Heideggerian because the purpose of the study was to be descriptive rather than ontological.

Although broadly speaking the phenomenological approach draws meaning from complex realities through careful analysis of narrative, subjective materials, the literature debates a true phenomenological method. Despite this diversity researchers involved in phenomenological methodologies agree that their central concern is to return to embodied, experiential meanings aiming for complex and rich descriptions of a phenomenon as it is concretely lived (Finlay, 2009).

Essentially the goal of this methodology is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from peoples’ viewpoint or frame of reference (Polit & Beck, 2006). It is not within the context of this chapter to fully discuss all the various approaches phenomenological researchers may choose in phrasing their research questions, such as heuristic, life-world, critical narrative approach and relational approach.

It is important to understand that methods vary subtly, and “share a similar focus on describing lived experience and recognizing the significance of our embodied inter-subjective life-world” (Finlay, 2009, p.2). Therefore, when choosing the methodology to research the lived experience of bedwetting in young adults and capture the whole meaning and concrete structure of the given subject or co-researcher, as defined in Giorgi's existential phenomenological approach, it was essential to remember that this phenomenological method goes from a concrete description of the subjects experience to the interpretation without any premature analysis. Because it was considered important to start with this concrete description of bedwetting, Giorgi's method was chosen for this study.

3.4 Research design: Giorgi's method of phenomenology

Amedeo Giorgio's method of phenomenology (Giorgi, 1985) which is rigorous descriptive empirical phenomenology was inspired by Husserlian ideas and situated within the perspective of the French Existential Phenomenological philosopher Merleau Ponty from the Duquesne School of Phenomenology. Giorgi's method is based on four principle characteristics: it is descriptive, it uses reduction, it searches for essence of the human experience and it is focused on intentionality (Giorgio, 1985). Elsewhere Giorgi (1997) more straightforwardly argues that his approach to phenomenology encompasses three interlocking steps: (1) phenomenological reduction, (2) description, and (3) search for essences (Finlay, 2009). Giorgi (2008) is clear that the purpose of the method he has developed is to clarify the nature of the phenomenon being studied in a more traditional, normative, and scientific sense (Giorgi, 1994).

3.5 Bracketing

Contemporary phenomenology, applies a mixture of phenomenological concepts such as bracketing and the value of understanding the lived experience (Roberts & Taylor, 2002; van Manen, 1990). Descriptive phenomenological studies involve the four steps of bracketing, intuiting, analysing and describing (Polit & Beck, 2006). Bracketing in qualitative research is usually described as a process of “putting aside one’s own beliefs, not making judgments about what one has observed or heard, and remaining open to data as they are revealed” (Streubert & Carpenter, 1999, p. 21). According to Giorgi bracketing involves a process whereby “one simply refrains from positing altogether; one looks at the data with the attitude of relative openness” (Giorgi, 1994, p. 212). The researcher attempted to remain open to the meanings attributed to the study phenomenon (Wall, Glenn, Mitchinson & Poole 2004). As Giorgi (1994) claimed that to eliminate subjectivity is not the answer rather the researcher’s ability to be objective is what really matters (Finlay, 2009). Phenomenologists also concur about the need for researchers to engage a “phenomenological attitude” which leaves the researcher open to the “other” and to attempt to see the world freshly, in a different way (Finlay, 2009).

Throughout this study, the researcher reflected on how her personality and knowledge of the subject area may bias or impact or compound research outcomes. The ten tips outlined by Ahern (1999) to enhance reflexivity and the researcher’s ability to bracket were useful in this process. This work gave structure to self-evaluation and journaling that led the researcher to;

1. Document any personal issues, and discuss these issues so as to remain with an open mind to complete the study.
2. Be mindful of areas of subjectivity that could influence the interview process or the data collection aspects of the study.
3. Keeps an open mind as to conflicting thoughts concerning the study, for example indifferent responses from each of the participants.
4. Did not experience any untoward problems with gatekeepers, minor issues were managed in a consolatory manner.
5. Discuss with colleagues (supervisors) issues that were particularly sensitive.
6. Take each new participant's data and recognize it as their story and not being concerned regarding new information, however conscious of information that may be repeatedly different.
7. Remain focused on the research time plan and completed the necessary application for extended time, constantly liaising with Supervisory staff.
8. Consulted the literature to gain a structure for the writing up stage in consultation with Supervisory support.
9. Prior to commencing the study the researcher had completed a substantive literature review from the interest gain from a pilot study ten years prior. This literature review was from a wide range of journals and the researcher made contact with experts at overseas conferences to gain further information and discussion on the subject, so as to prevent a narrow perspective on the subject.
10. All transcripts were transcribed by an independent source and many meetings with Supervisory staff were held so that learned colleagues were reading and

re-reading the outcomes of transcripts to ensure against bias during the analysis.

3.6 Procedure for recruitment of participants

Purposeful sampling, which involves selecting participants with knowledge and experience in the phenomena under study who are willing to share their story with the researcher, was used for this study. The logic and power in purposeful sampling lies in selecting information rich participants who provide expansive and full descriptions of the phenomena under study (Polit & Beck, 2010).

Despite a variety of procedures initiated by the researcher to gain access to potential participants the recruitment period was long and tedious. Initially radio advertising with Curtin FM and Fremantle 107.9FM, in Perth Western Australia was employed and this advertising continued for 12 months during 2008-2009. Advertisements were also placed in six local community newspapers with a distributorship of 397,654 households (Appendix A). Furthermore, 500 posters were distributed via colleagues', family, friends, and company representatives of products for incontinence, state wide from Broome in the far north of the State to Albany in the south. These posters were hand delivered to general practice clinics, specialist urologist clinics, public libraries, shopping forums, and placed behind toilet doors at many venues such as (Appendix B). In the latter part of 2008 a further 200 posters were printed. Although extensive recruitment methods were employed only a small number of participants came forward due to the nature, sensitivity fragility and "secret world" of the subject being researched.

When contacted by participants the researcher outlined, over the phone, the nature and objectives of the study. Each potential participant was sent an information sheet outlining the study and their rights as participants. The researcher asked potential participants to contact her when they had read the information sheet to make a time for the interview session.

3.7 Ethics

Ethics approval was obtained from Curtin University of Technology Human Research Ethics Committee. All participants were informed of the voluntary nature of their participation and given an information letter (Appendix C). All participants gave written consent (Appendix D) prior to participating. The researcher retained the original of the consent form and the participant was given a copy for their records. Permission was obtained from the participants regarding any publications and presentations of the data, with assurance of confidentiality of personal details. Given the sensitive nature of this topic, a referral process was established and offered to any participants that asked for assistance with their problem. In line with the University's risk policy all participants were referred to the Urologist (researcher's supervisor), at the Hollywood Urology Academic Unit for clinical review, and continue to be managed. Referral to a clinical psychologist was discussed with one participant, and appropriate information was forwarded in the mail to allow this participant to make a personal decision regarding an appointment. The researcher's telephone number has been given to all participants for use if required for future clinical management.

The researcher had a complex and in-depth understanding of the subject that ultimately did assist the participant's with the discussion of individual issues raised, and outside referral resources as needed. Recruitment rates may have been affected by a number of factors. Firstly, the embarrassment felt by potential participants, their feeling of inadequacy, the threat of disclosing a life-long secret and the myths surrounding adult bedwetting all obviously posed a threat to participants. The interviews had some degree of stress experienced by both researcher and participant due to the reciprocal nature of their relationship (Sque, 2000). The researcher was fully aware of the role she had in the interview process and the impact it had on the participants, and that the collection and the quality of the data would be dependent on technique and ability. All participants were offered follow up clinical intervention by the researcher's medical supervisor if they wanted to pursue this option. To maintain confidentiality, all data has been de-identified, coded and stored in a locked filing cabinet. The content of the tapes have been erased, this followed the completion of the study, and the data retained for five years by the researcher. The researcher and immediate supervisors are the only persons who can access this data.

3.8 Data collection methods

3.8.1 In-depth interviews

Data for phenomenological studies are primarily collected from in-depth semi-structured interviews and supported with data from other sources such as diaries, field notes or artwork (Polit & Beck, 2006; Portney & Watkins, 2000). The researcher is regarded as an instrument in data collection and their ability to make

the participant feel at ease during the interview process enabling them to openly share their story is an important skill in obtaining quality rich data (Eide & Kahn, 2008). While having had a phone conversations with participants during recruitment when meeting the participant for the first time the researcher again established rapport with them to make them feel safe and at ease with the future interview situation. Each interview was conducted at a time and place that was safe and convenient for participants. All interviews were conducted during daylight hours.

The audio taped and transcribed verbatim as soon as possible after the interview was completed providing raw data for phenomenological analysis. Before each interview commenced the researcher again explained the objectives for the study and gave the participant another copy of the information sheet and allowed time to answer any additional questions participants may have (Appendix C). Each participant was then asked to sign a consent form (Appendix D) and the researcher reiterated to the participant that all data arising from the interview would be de-identified and at no time would their identity be disclosed. Prior to the interview commencing a descriptive profile (Appendix F) was given to each participant to collect their demographic information such as age, living arrangements, education level, duration of symptoms, and any previous contact with health care professionals. To preserve the subjects' true depth and dimensions of their feelings, thoughts, and behaviors, data for this study was collected using an interviewing technique involving engagement and sensitivity.

The semi- structured interviews then commenced (see Appendix E- interview guide) and prompt questions were utilized when necessary to assist participants to provide full and rich descriptions of their experiences (Appendix E) (Roberts & Taylor, 2002). Data were also recorded through written notes. Each interview began by the researcher asking the participant “Tell me about your bed wetting experience”. During and after each interview the researcher also documented relevant contextual experiences and field notes to ensure that all non-verbal information was captured during each interview. As previously stated the researcher was aware that the stories that she would hear during data collection would be of a very sensitive nature and therefore, she placed emphasis on engaging with each participant and conducting the interviews in a sensitive and safe manner. The researcher was well aware that for most of these participants it was the first time they were sharing their experiences of living with bedwetting with anyone outside of their immediate family and general practitioners/specialists that they had seen to try to find a solution for their problem. Interviews were also spaced at least a week apart, to give the researcher time to reflect on the data collected and to plan for the next interview session (Sque, 2000).

3.8.2 *Data saturation*

Typically phenomenological studies involve a small number of study participants – often ten or fewer (Polit & Beck, 2006). It was anticipated that up to ten young men be interviewed for this study. However, the final sample size was declared with the sixth participant interview when no new information was obtained and data saturation was achieved. At this time the themes were well identified and expansive in their descriptions (Burns & Grove, 2007). This number of

participants fits well within what is recommended by Giorgi who stated that at least three participants should be included in a study in order to come up with the essence of the lived experience (Giorgi, 2008).

3.9 Data analysis

In applying Giorgi's four characteristics of analysis to this research, the preparation of a structured questionnaire "tell me what it is like", allowed communication from the participants, which was concrete and descriptive and with the use of follow-up questions avoided any kind of premature analysis or explanatory constructs. These interviews were audio-taped to capture the exact meaning as described by the participant. This allowed the researcher to reproduce the meaning, as given by the participants as a whole, this Giorgi refers to as 'Gestalt' or unified form, and as it appeared from the participants' conscious point of view therefore applying an important phenomenological concept of intentionality, which is what the participant is experiencing and how, or the relationship between persons and situations (Giorgi, 2008)). By repetitive reading of the transcripts, the researcher took the meaning of these experiences as it was presented and in doing so, addressed the concept of reduction, and differentiated between the meaning units, therefore centering on the phenomenon being studied and moving on further to look for the invariants and unchangeable characteristics of the particular phenomenon under study. Giorgi refers to these meaning units as key terms, aspects, and attitudes, (or capturing the insights), and by dividing these, the analysis is made easy and more manageable. (Finlay, 2008). Continuing analysis by the researcher in this study within the parameters of the Giorgi methodology was to transform the meaning of the units into a consistent statement about the participant's experience, which included articulating

the psychological insight and synthesising all of the transformed meaning units into this consistent statement, referred to as the structure of experience (Polit & Beck, 2006).

Initially and as part of this data analysis, a transcript was shared with supervisors to ensure credibility of the data. Intuitively it was important that the researcher remained “open” to the meanings attributed to the phenomenon by those who have experienced it and creatively vary the data until such understanding emerged (Morse, 1998). After extraction of all significant statements, duplicated statements were deleted in accordance with the Giorgi method of phenomenological analysis.

3.10 Trustworthiness and credibility of data

Trustworthiness and credibility of findings are issues of concern in qualitative research primarily due to the subjective nature of the data (Portney & Watkins 2000). Problems arise because the same words may have varied meanings in different situations, however “the quality of any phenomenological study can be judged in its relative power to draw the reader into the researcher’s discoveries allowing the reader to see the worlds of others in new and deeper ways” (De Castro, 2003, p. 55). Adherence to the chosen research design and steps of data analysis also add to the trustworthiness of the data. Checking of data is also important and participant interviews were checked for consistency in coding by the researcher’s supervisors further ensuring credibility of findings. A decision or audit trail according to Polit and Beck (2006) is a systematic collection of documentation that allows an independent auditor to come to conclusions about

the data. The researcher endeavored to ensure the maintenance of all raw data, data reduction and analysis, process notes materials relating to intentions and dispositions, and drafts of the final thesis showed consistency and depth of this audit trail. Furthermore, regular reviewing of the research methodology and analysis of data in discussion with supervisors and peers assisted the researcher to debating the interpretation of the findings and assess the internal logic of the report. Rich descriptions from participants presented within this thesis also add to the trustworthiness of data. Finally and as discussed in Polit and Beck (2010), comparison of findings with existing literature is an essential step in ensuring trustworthiness and credibility of data collected during this study (Yeung et al., 2004; Hirasing et al., 1997).

3.11 Summary

This chapter details the use of the phenomenology as a research method to collect data on the lived experience of young men who have bedwetting. The data were obtained from: interviews with participants who had direct experience with the phenomena under study, contextual documentation such as field notes made by the researcher along with background information, analytical documentation of decisions made arising from data analysis and Giorgi's 4 principles characteristics of data analysis. Purposeful sampling techniques were used which led to the emergence of the theme: "Hiding the problem". Hiding the problem and its three sub themes will now be presented in chapter four of this thesis.

CHAPTER 4: Results

4.1 Introduction

This chapter presents the findings of a study using Giorgi's method of phenomenology to describe the lived experience of male youth who have persistent bedwetting. The major theme titled "Hiding the problem" and three sub-themes were identified that together provided rich descriptions of young men's lived experiences of living with bedwetting. The six men who volunteered to participate in this study were from various socio-demographic backgrounds, and their ages ranged from 19 to 27 years with a mean age of 24 years.

Two participants had graduated from school in year 12 with a tertiary entrance qualification, three were or had studied at technical colleges, and one participant was enrolled at university. Five participants had full time employment and they were satisfied with their work and occupational choices that included being a tire fitter, mechanic, personal training, accountant and a truck owner-driver. Two participants lived alone, two lived in their extended families, one shared accommodation with three female colleagues from university, and one lived with a female partner. This participant was the only one of the six currently in an intimate relationship with another person.

While participants were not formally asked about their family dynamics during the interviews they all disclosed that they were from families with one to four siblings, and of these only one female sibling (participant B) had wet the bed up

until 10 years of age. None of the other participants were aware of any bedwetting history within their families.

Two respondents who initially answered advertisements to participate in this study later refused to be interviewed. The researcher did not persist in their participation, but they were assured that help was available in the form of treatment and that they could telephone the researcher in her professional position in the future if they wanted assistance with their problem. The ethic of caring as stated by Eide and Kahn (2008, p.205) is that “all efforts be made by the researcher to ensure alternative forms of support for participants”.

The major theme of “hiding the problem” began for all participants from the time when they first became aware they had a problem and as a result they were different from their peers. For all participants in this study this awareness crossed the developmental stages of pre-adolescence, adolescence and young adulthood (the developmental stage that all participants were in at the time of being interviewed for this study). Hiding the problem was employed by participants as the way of coping to their experience of living with bedwetting. As participants moved through the three developmental periods they spoke of different life events and circumstances that were paramount in each of these stages for hiding the problem. Whether concerning the family, peer relationships, school, sporting or intimate and personal relationships from the time they first became aware they had a problem to the time of the interview there was increased pressure placed upon all participants to hide the problem in order to function and live within society.

Participants described that during the stage of pre-adolescence the problem was hidden within the family and they were not particularly worried about their incontinence as they assumed it would go away as they grew older or their parents would find a solution to the problem for them. As participants moved into the adolescent stage of development they began to realise that they were different from their peers and their bedwetting was a health problem that had the potential to impact on all areas of their lives. Living with bedwetting became a constant struggle for participants and shaped their identity and the life choices that they made. At the time of interview participants were in young adulthood and spoke about being increasingly socially isolated and how their bedwetting had been a significant influence on their life choices, for example, their occupation. At the time of interview they had also become resigned to the fact they were now living with an incurable chronic illness that would be present for the rest of their lives and were trying to find ways of managing this illness within their life experiences. Each of the sub-themes of hiding the problem will now be presented.

4.2 Hiding the problem

Hiding the problem was the main theme that emerged from all formulated meanings identified during data analysis. For participants, hiding the problem occurred through all of the three developmental stages from the time they first recognised they were different for their peers until the time of interview. Hiding the problem impacted on their lifestyle, their life choices and resulted in their social isolation and feelings of hopelessness that they could do little but to hide from society:

I think I'd be twenty times more confident, and could try new things, and if you could associate bedwetting at my age it affects your self esteem, and

confidence and so many other things that are not directly attributable to the bedwetting, but has many ripple effects and partly determined the course of the career I've chosen. I've probably not made certain decisions on my career due to lack of confidence (Participant E).

Hiding the problem contained three sub themes which were: 1) pre adolescence: hiding within the family; 2) adolescence: struggling; and, 3) young adulthood: social isolation. These three sub-themes enabled the researcher to describe participants' lived experience of wetting the bed and to provide rich descriptions of these experiences in this thesis.

4.2.1 Pre adolescence: hiding within the family

The first sub-theme of hiding the problem occurred during the developmental stage of pre adolescence and it was called hiding within the family. Hiding within the family began when participants became aware that their bedwetting was abnormal and that other people of their age did not have this problem. However, during this phase of the life cycle, the problem was hidden within the family who in this initial stage of the bedwetting problem played a pivotal role in supporting participants to seek solutions to the problem, for example, seek medical intervention. "I've done everything, mum has done a fair bit and since I was little I've been to Princess Margaret Hospital and in my early teens to [a country] hospital for the same tests" (Participant F). All participants spoke of being in very supportive families during this time of their lives and as a result they were optimistic that a solution to the problem would be found: "My parents obviously know what happens and they just don't make a big deal out of it [bedwetting] in front of other people. Also it was my sister who saw the advertisement and asked me to contact you [the researcher]" (Participant D). At this time the family took on much of the burden of hiding the

problem and participants were not overly distressed as they believed that it was a short term problem that would be solved. All participants reported that during this time their mothers usually played a very significant role in supporting them within the family unit believing the participant would just grow out of it: “Mum always said you’ll grow out of it [bedwetting], it’s just a phase and just a problem now” (Participant A).

However, it was during this time that participants first became aware that they were different from their peers at school and of the need to hide the problem from people outside the family. Hence their illness began to impact on their ability to live a normal life and started to be problematic for them when they were invited to take part in social or recreational events that required them to sleep outside of the family home. For example, sleepovers or school camps: as one participant explained: “through primary school there were a lot of camps I didn’t go on [them]. [I] just kept to myself mainly due to embarrassment because no one else had the problem” (Participant C). Discretion about, and concealment of their problem was extremely difficult but participants knew it was vital that their friends did not know that they wet the bed:

I just found ways to hide the fact you know [that I wet the bed] and pretty much no one that I went to school with, no one I went to primary school with, all my mates I hang out with now, still don’t know (Participant D).

All participants expressed that they had strong matriarchal influences in their lives during this time that protected them from both indifferent family members and from their peers. They supported participants by cleaning up after their bedwetting and by

shielding them from further embarrassing situations. The following participant clearly expressed these beliefs:

Mum [would] cover for me again? How would she save her son again when people would come over? I would go away with a group of friends or something like that [or] other kids [would] come into my room, [and it would be mum who would cope and disguise the problem]. It was tough... growing up and only having me and my mum know about it [bedwetting] and maybe a handful of doctors, no one else in my life apart from you [the researcher] (Participant A).

During the interviews participants often had tears in their eyes and required to pause in their stories when describing the support and the role their mothers played in their lives. The participants were respectful and grateful for this support:

Mum took me along on these [appointments] and supported [me and] never, never put me down or anything for having the problem [bedwetting]. She never suggested it was my fault. You know, as a young adult mum [she] would try and broach the subject at times but I just didn't want to talk about it with her. I wouldn't want her to hear this [now] you know [said to the researcher] (Participant B).

It was the strong support obtained from his mother that enabled one participant to try to attend a year twelve camp, despite his feeling of embarrassment about the possibility of being exposed as a bed wetter in front of his peers:

I don't know, I can't remember exactly how I did it now. I knew my year coordinator, my mum had gone and seen my year coordinator and so I was, you know this stuff happens [school camps] and it's something I've just got to go through. It's embarrassing but somehow I'm going to try and cover up [the problem] just so I didn't have to deal with all the rubbish because I had hidden it (Participant D).

Other positive supports came from their grandmothers as one participant explained:

[My grandmother encouraged me] "to do something about it" [his bedwetting]

(Participant F). It was clear that in their pre-adolescent years participants relied mainly on the protection of the family unit to hide the problem and that their mothers

played a key role in supporting participants to do this. However, not all family members were supportive and therefore their mothers hid the problem from these people in order to protect the child: “So mum and I sort of hid it [bedwetting] from him [participant’s father]... (Participant A). When participants’ fathers were supportive they often suggested strategies such as restricting fluids as a form of management for their son’s bedwetting problem. One participant described this strategy when on family holidays:

Yes we went on several holidays. I wouldn’t drink at night, I wouldn’t have water or orange juice or whatever [drinks were offered] to keep my bladder dry. That was [a technique I used] when I went away and that was normally my dad’s advice. I couldn’t have tea you know like [other people] after dinner (Participant E).

However, most fathers displayed indifferent behaviours towards their son. One father resorted to smacking his son as he believed he could control his bedwetting and that discipline was a means of making him exert this control:

I remember when I was a young kid and he’d [the participant’s father would] come into the room and either smack the hell out of me or say it was my fault (Participant A).

Participants also experienced being made fun of by their siblings because of their bedwetting. Two sisters who just loved to “rubbish him” caused one participant further dysfunction (Participant F). However, other participants also had positive and indifferent responses from their sisters, one not choosing to know about the problem of bedwetting and another who showed empathy and understanding towards their brother:

Oh I’m, well I’ve got a sister and she understands, she doesn’t put me down and that, she knows that I’ve got to work through it and so do I but she also knows that it’s something that’s going to happen and it often will, so all my

family have had to deal with it [my bedwetting] from early [in] life (Participant D).

Another participant experienced this response from their sister:

I've got an older sister, but she has never experienced anything [bedwetting]. She hasn't had the problem herself. I know she knew about it at a young age but I'd say she's in the same boat as my dad; she would know about it or chooses not to know about it I don't know (Participant A).

In summary, during the sub-theme pre adolescence: hiding within the family participants felt supported within the family environment and the family shielded much of the responsibility for the participant's problems. There was a feeling at this time that there would be a solution to the problem and that participants would then be able to live a normal life. However, this was also the time when participants became aware that they were different from their peers and that they needed to hide the problem in order not to be seen as being different or ridiculed.

4.2.2 Adolescence: struggling

The second sub-theme of hiding the problem was called struggling and it was identified in the data when participants moved into the transitional period of adolescence. During adolescence participants began to struggle for the first time with having to live with bedwetting and of taking ownership of their health problem:

There were times when you did sleep over at friends houses and it did happen and then I'd try and cover my own tracks and it became a game of survival of the fittest, so no one would find out (Participant A).

As adolescence is a time of determining identity, participants' bedwetting practices began to impact on their identity and relationships with their peers. While they were

adjusting to the challenges of this developmental period their bedwetting began to emerge as a major focus in their identity formulations and in their ability to form and sustain peer relationships. As participants entered adolescence it became clearer to them that this was a problem that could impact on many areas of their lives and which they may struggle to find a solution for.

Of prime importance to participants during this time was the acceptance and support of their peers. This acceptance also meant that they needed to take part in peer activities such as attending senior camps, taking part in sporting activities and generally belonging to the group. Participants struggled to conform to peers expectations and when they did they often experienced embarrassment and shame. The possibility of waking in a wet bed or their friends smelling the odour from their enuresis was so great that participants began to avoid such situations at all costs.

Occasionally I will enjoy myself and I'll forget about it [bedwetting] and have a good night out with my brother and friends, and then I wake up and I've wet the bed and have to clean all that up and the horrible smell coming out of the bedroom just takes the whole pleasure off the weekend (Participant B).

As a way of coping with the struggle over embarrassment and shame that they experienced participants began to live a "Jekyll and Hyde" like clandestine existence as one participant described:

... you live life as a young person but then as time goes on you start to get into your teens and into high school and , it [bedwetting] becomes a real issue then; embarrassing. You are always trying to hide it [the bedwetting] or cover it up and you're still trying to go out and be with your mates and with your peers and do all that sort of stuff (Participant F).

Another participant described his struggle to hide his health problem from friends during a sleep over at a friend's house as: "a game of survival of the fittest or something you know, that no one else does" (Participant A). While adolescence is a time of establishing friendships and it is clearly expressed by one participant that during this period of his life he had great difficulty in moving forward at this time:

I've never really been very much into making friends. I am sociable, very sociable, I always was but obviously there was a point, a point in my life between the ages of twelve, to fifteen where I was very antisocial [due to bedwetting]. You know the minute you make a friend then you know for a friendship to grow, getting closer they've got to know you, you've got to know them and you know I wouldn't want someone to know too much if there's a risk of what they'll know you know they won't like. So when it came to friends I was very apprehensive. We were friends at school that's all, I'd never bring a person home and I'm still like that today (Participant E).

Hiding the problem created in participants an array of emotions and behaviours that they struggled to manage on a daily basis. During the interviews they spoke of conflicting feelings about how they fitted into society and about their struggle to use coping strategies to ensure the problem was hidden from those around them:

It is sort of one of those things [bedwetting] you've had to keep secret for your whole life and have looked upon as if it's [was] your fault or if it's a disease or anything and you're none the wiser for it you know. It's not like you can control it (Participant A).

It was apparent to the researcher that the term given by participant's to express bedwetting, "the problem" was a further indication of hiding the problem and their struggle to cope with what was happening to them. Descriptors such as 'it' and 'that thing' were just two terms commonly used by participants. For example: "it was always there but it was something that was always thought about and talked about, depends on who it was" (Participant F). A further example (Participant B) was 'that

thing' [referring to his bedwetting] had an impact towards the end of primary school and start of senior school when, like the obvious one is attending school camps.

"Straight away that's where you go into your shell". A further description by another participant suggested:

So yeah it's been ... really hard. Probably most difficult because it's the silence you know, you don't know who to talk to about it, can't even talk to your mum about it because she'll be like you know, I didn't know you were still making puddles at this age (Participant E).

Participants were very frank and graphic with their stories about their illness and the researcher could feel the energy from participants while they were describing the problem, which was suggestive of a shame element or that they in some way were responsible for their problem: "So it's one of those things I have had to keep secret as the problem is looked upon as my fault" (Participant A). Participants spoke of strategies that they used to hide their bedwetting which included denial or not talking about the problem for fear of being stigmatised:

In the family it was always talked about and made fun of I suppose which I didn't like, obviously, and I got very pissed off about it and words to certain people were thrown around rooms; so I think at the end of the day we all learnt our lessons; just stay away from that subject (Participant F).

It was clear that participants' felt the need to adapt and introduced strategies around lifestyle changes to assist them to manage their bedwetting and to alleviate their suffering. One participant struggled with the embarrassment he experienced when he attended a bedwetting clinic in school uniform from the age of approximately 13 years: "I didn't want to go along to the clinic [bedwetting clinic] from about the age of thirteen or fourteen, going along after school in your school uniform and people recognised it" (Participant B). Participants also struggled with the despair they were

beginning to realise that there may not be a solution to their problem and that he was still wetting the bed at eighteen years of age:

It's just gone backwards, is the only way I can put it. I was still quite resilient growing up with it, but at the age of fifteen was probably the first decision where I had to pull out of something, being rugby at the time. I went through all the tests and the trials that I've talked about at the beginning, and doctors say oh you know it'll sort itself out in good time and you know when it got to sort of eighteen, nineteen and it still hadn't sorted itself out, things just started going backwards from there (Participant B).

As participants struggled, experiencing feelings of embarrassment and shame which led to low self-esteem and as a result they became severely inhibited in their psycho-social development due to the burden of wetting the bed:

[It is] embarrassing, being at such an age, it's just an embarrassing feeling as I can't go out to friend's places, stay overnight or whatever and have the problem of this [bedwetting]. So my social life is not too good at the moment (Participant C).

Participants were also aware that other family members struggled to cope with the fact that a member of their family was still wetting the bed during adolescence. One participant explained that his parents separated when he was eight years of age and he now felt that his father was embarrassed sharing with his new partner, that he had a son who wet the bed.

...dad was pretty cut up about it, because I wet every night and you know, he didn't understand it and he still doesn't understand. I think it affects him as much as it affects me, and it's embarrassing for him (Participant F).

Another father resorted to smacking as a disciplinary action which suggested "it was his fault" (Participant A). Participants struggled with simple strategies to manage

their bed wetting each morning when it began to become a source of embarrassment even in the home environment:

I have tried every program [related to the bedwetting] and tried hard on the program, and it was not comfortable, but now I am starting to grow out of the problem, having fewer nights when I wet the bed. It's good as I don't have to be embarrassed walking through the house with the laundry (Participant D).

The inward struggle that participants were constantly engaged in was a driving factor in their avoidance of situations where their secret could be exposed. Sport featured prominently in one participant's story but he refused to go away on the weekend to a sports carnival sleep over in case he wet the bed. His struggle gave him no choice but to pull out of all sport from the age of 15 years. As a result he struggled to fit in with his peers and became overwhelmed emotionally when hassled:

You know I've been an active sports person since a young age, all sorts of sports, rugby union was the main one and then you get to that older age and you, it's [bedwetting] still happening and you've got away games and you know tours and things like that happening, and you feel no choice but to avoid them. This was definitely in the forefront of my mind when I was probably about fifteen. That resulted in me packing in something that I loved dearly from the age of fifteen (Participant B).

Participants continued to struggle throughout adolescence and did not know how to manage the normal tasks and challenges of adolescence. They were aware of changes in their psycho-social development which resulted in them wanting to spend more time with peers and less time within the family unit. However, they struggled to see how this was possible as they began to realise that there may be no solution to their problem and that they may continue to wet their bed for the rest of their lives: "am I going to get to 21 years of age and then 35 years of age and still be doing it [wetting the bed]. Things like that sort of rack your brain I guess" (Participant A).

In summary, during adolescence participants struggled to cope with their bedwetting problem which began to impact on all areas of their lives. Increasingly they began to realise that they were becoming isolated from both their family and from their peers. They also struggled with the fact that there may not be a solution to their problem. The participants also realised that they were increasingly alone and as they moved away from their family unit they were not able to replace the support found during earlier times with support from their friends and peers. Participants' bed wetting became the major focus of their lives and determined who they could relate to and what they could do and who they could share things with at a personal or intimate level.

4.2.3 Young adulthood – social isolation

The third sub-theme of hiding the problem was called “social isolation” and described how participants increasingly became isolated from family, friends and peers as they entered young adulthood. At the time of interview all participants were now in this developmental stage of life and were attempting to obtain some degree of normality within their lives. The family which had once been a major support to participants was no less supportive as separation and autonomy had occurred during adolescence. As a result participants were now largely responsible for all aspects of their lives. In socially isolating participants began to introduce even more constrictive coping strategies that place themselves away from others. They were frightened to date and to have relationships with other people. For most participants this isolation occurred because they were fearful of rejection by potential partners when the person found out that they had a bedwetting problem. The fear of wetting

the bed or waking in a wet bed had a profound effect on a participant when it came to a decision on whether to pursue further intimate relationships:

It doesn't stop me in the sense as in wanting to find another girlfriend but in the back of my mind I'm worried about you know what I mean what happens if they do stay over and that's the night something happens (Participant D)?

One participant had attempted a short relationship with a girlfriend for six to nine months however his anxiety was very high during this time. When he finally told his girlfriend the relationship ended which he described as a traumatising failure. This resulted in him not seeking future relationships and he became increasingly isolated and generally gave up and was left with feelings of despair and hopelessness:

I do lead quite an isolated life now, I did have a relationship when 19 years of age, however after a year it was torturing me inside, and I didn't know how to handle it so I told her and that is when the relationship ended, it pretty much destroyed me as a person. I was soul destroyed, and remember at the time I just bawled my eyes out for quite a while. I try to join the boys for a drink however I feel constantly stressed and do not enjoy outings and more (Participant B).

Another participant spoke of having had one intimate relationship which lasted for two years and during that time his girlfriend was unaware of his problem:

It was remarkable like whenever we slept together, I would never wet the bed, however nights that I wasn't sleeping with her I continued to wet the bed and this continued for the two years we were together, and she never found out about my problem (Participant A).

Unlike the majority of participants, one young man spoke of the fact that he had experienced an intimate relationship and gained enough confidence to tell his partner about his problem. She declared that although she had "grown out of the bedwetting every now and again she would do the same thing, she was born with it and she had family members who bed wet, not that she did it all the time, but she understood stating that it wasn't my fault"(Participant D). There was a strong sense of feeling of

an increase in restored self-worth emulating from this participant's story, as he spoke of regaining worth and self-confidence that all would be alright and he would be able to move forward in his life.

Another participant expressed how embarrassed and nervous he was just formulating friendships and not wanting to work in a team environment because of his lacking in confidence and self-esteem. This participant stated that it was very hard to disclose that at 26 years of age he was still wetting the bed and had only once attempted to bring a lady home:

I did attempt it once and you know, women are very instinctive definitely, you can't hide anything from women and you know she began to observe the room and she looked around, and I felt unnerved. Had she been through my laundry basket? I was so unnerved just thinking about it that I started saying I am a perfectionist, and generally making excuses. Nothing came of the visit, and I [now] definitely avoid getting too close [to anyone] (Participant E).

Participants reported that they believed having this problem of persistent bedwetting had impacted on their personalities. They also mentioned that friends had commented about their concern for the participants increasing social isolation, fluctuating personalities, moods and indifference to take part in social functions. There was a strong belief between participants that their illness had had a huge impact on their personality development inclusive of behaviour and attitude by constantly trying to balance the hiding of the problem: "a lot of people I've pushed away say that they feel there is so much more to me that I don't want them to know, and why aren't I willing to share and join it?" (Participant E).

Participants did not take part in any activities that had the potential to cause them distress such as sleeping over at a friend's house. Shared accommodation was out of the question for one participant when he was asked to move in with friends:

...it's like praying for this medical cure to sort of come along. Before he [friend] says are you ready to move in which has me thinking I don't have mum to look after me anymore. I know Mum is not going to be there and it's on my own, at 22 years of age, so do I stay home for the rest of my life? [there are] so many decisions to make (Participant A).

In trying to overcome their feelings of isolation one participant wanted to renew his sporting club membership, however as aptly expressed he felt the option wasn't there due to the anxiety and fear of being asked away again on travel trips:

I did actually start playing again when I was eighteen. I got talking to a guy I was working with, become friends with and went along and started playing rugby again on the weekends so I did manage to get back into it, but again, I go back, again when the tour times comes round, just the anxiety and you know obviously a fear of going on them left me no choice but to pull back out of them. This night problem caused a lot of anxiety, and I developed accidents during the day that I think were mainly anxiety. I've got over those now and don't know whether it is because I have accepted the problem (Participant B).

The fact that one participant suggested that he may have made different decisions within his career pathway, implying certain decisions were governed by a fear of disclosing the problem of bedwetting:

...if you can associate bedwetting at my age, it has a lot to do with, and affects your self esteem, affects your confidence, affects so many other things that are not directly attributable to bed wetting, but it has so many ripple effects, and we don't know but may partly determine the course of career I've taken. I've probably not made certain decisions on my career with the confidence and self esteem that I could have, if I was not wetting my bed (Participant E).

The following participant made definite reference to their concerns regarding the effect their obvious social isolation was having on their personalities.

Yeah it is, and as I say it's been a gradual backwards step from sixteen, eighteen to now it's just constantly feel there's no choice but to pull out of social situations and to the point where I do lead quite an isolated life now. Well not really, I mean I work and I also study to keep myself you know interested in things, but socially is a different story (Participant B).

One participant discussed mood changes and suggested this was possibly due to his bedwetting and it also affected his choice of employment:

So the scary thing is I don't know how much this [bedwetting] has affected me you know. I do have a lot of withdrawal, you know withdrawal symptoms so I wouldn't want to work with teams, because sometimes I'm very bubbly and, I'm in charge, other times I just don't want to talk if I've had a very bad morning. I just don't want to talk to anyone. So obviously you can't work in the sort of jobs where teamwork is essential. I don't like getting too close. I don't like getting too close to people (Participant E).

There was a strong feeling within this interview that the participant wanted to express the fact that his problem of bed wetting had impacted greatly on his personality:

... a lot of people I've pushed away they say that there's so much to you that you don't want us to know. But then so much is so good, and it's just amazing and why are you not willing to share that with anyone and I'm like, and I'm like well when I'm ready I'll let you know. I always come up with all these excuses (Participant E).

Participants expressed feelings of hopelessness about being isolated from others and in their ability to maintain this "veiled" existence. At this time of the interview the researcher became very aware of the total impact on the lives of these young men that their illness had:

You know as a young adult mum would try and broach the subject [bedwetting] at times but I just didn't want to talk about it with her. If ever the subject came up it's not something we'd talk about and as I say it's not something I want to talk about with her either. I would pass the subject on because I wouldn't want her to see how, I mean obviously she has an idea but I wouldn't want her to know about how difficult it was for me (Participant B).

Managing and trying to live with the burden of bedwetting consequently saw the participants become more and more socially isolated and totally responsible with minimal personal support, to devise many ways to cope with this severe life event. All participants suggested that the most effective way to cope with their problem was to hide it or keep it a secret, and to conceal it:

I feel I have no choice because I'm healthy and I believe in acting on things, changing things if you can, but for me there is no other choice but to keep this problem [bedwetting] a secret and suffer in silence (Participant B).

In managing the impact of social isolation one participant expressed the following feeling of relief, philosophically stating that; "It's not whether it's male or female, being around a partner, men and women are much the same, and we all need love and affection and the physical side"(Participant F). Keeping busy, with further study, watching footy all weekend, and doing chores around the house, were coping strategies one participant used to suppress the overwhelming feeling of the social isolation he experienced :

I work fulltime during the week and do a few chores weekend, and I am studying sports science. I quite like that extra activity, and find it very interesting, and it kind of plugs a hole in the social inactivity (Participant B).

At 15 years of age (now 23years) one participant visited a general practitioner (GP) and was given medication resulting in a reduction in episodes of his bedwetting, however the problem persisted, and due to work and study commitments, socially isolated to the point of stating that he really had no time to follow through for help:

Time was an issue, just with work and all that sort of stuff, I just do work and I go to TAFE and there's no way I can get home in time and get back out to deal with this problem. I've just accepted it and try and seek help, that's all you can do. You can't beat yourself up over it (Participant C).

In trying to interact with others one participant used what appeared as practical means to cope with his problem of continuing to bed wet. These included, days of not drinking. Another participant had persisted through a pathway of treatment strategies to try and cope with his bedwetting but as everyone failed he became more and more isolated:

I tried everything from acupuncture to herbal remedies, searching high and low for anything. I visited the GP which resulted in a whole array of medical things to try, ending with the GP stating he had nothing further to offer, and until new research was found I am relying on my own strategies (Participant A).

One participant had not seen a doctor for ten years, stating that he had done all the treatments, nasal sprays, alarms to wake him up during the night, including catheters into his urethra (diagnostic test) and stating: “I’m not doing that ever again”(Participant B).

Most participants had tried some form of intervention in their earlier years, and the mechanisms revolved around some very pertinent stories of deep feelings and emotions. Lacking in confidence and becoming more and more socially isolated one participant expressed the following:

I think I would be twenty times more confident, and could try new things, and if you could associate bedwetting at my age it affects your self esteem, and confidence and so many other things that are not directly attributable to the bedwetting, but has many ripple effects and partly determined the course of the career I’ve chosen. I’ve probably not made certain decisions on my career due to lack of confidence (Participants E).

The possibility of waking in a wet bed or their friends smelling the odour from their bedwetting was so great that participants began to avoid these situations at all costs. “Occasionally I will enjoy myself and I’ll forget about it [bedwetting] and have a good night out with my brother and then I wake up and I’ve wet the bed and have to

clean all that up and the horrible smell coming out of the bedroom just takes the whole pleasure off the weekend”(Participant B). Although not directly attributed to social isolation one participant experienced a recent incidence which focused on the way our psychosocial well being may be traumatised. Waking in the early hours of the morning because he had wet the bed, the participant changed the bedding and dozed off to find he consequently slept through the alarm and a pending university exam: “I just got up and dressed for the exam and was revising my work and I dozed off for an hour or less” (Participant E).

4.3 Summary

In summarising the experiences as described by the participants in this phenomenological study within the three developmental stages of pre-adolescence, adolescence and young adulthood it is clearly defined that there appeared only one option to them and that was to hide the problem. Within the major theme of hiding the problem participants in the pre-adolescent years were dependent on family support, which was part of accepting the problem for them at this age. Experienced by all in the adolescent years, were the struggling issues including peer identity, taking more responsibility for their problem, and developing some of the decisions required to cope with their problem of bedwetting on a long term basis. Also at this time [adolescent years] emerged the feelings of embarrassment, poor self-esteem and the struggle to feel confident that develops during this developmental period. Young adulthood, the age that all participants were interviewed disclosed and highlighted the participants experiences of socially isolating as a means of coping with their problem [bedwetting] and trying to deal with what appeared at this stage in their lives to be life long with no means of resolution. Most pertinent at this stage in their

lives was the personal options including the spontaneity to develop an intimate relationship.

In conclusion, if we are to consider a review from the developmental literature linking healthy adjustment to “five core competencies of positive sense of self, self-control, decision-making skills, a moral system of belief and pro-social connectedness” (Guerra & Bradshaw, 2008) then there is clear evidence within these transcripts that the participants are at risk of retaining certain elements of negativity and deprivation with low self-esteem deemed to continue through the remainder of their lives. Discussion regarding the findings from this phenomenological study that interviewed young males aged 19years – 27years about their lived experience of bedwetting are in the following chapter.

CHAPTER 5: Discussion and Recommendations Of The Study

5.1 Important findings

In this phenomenological study the researcher set out to describe the lived experience of male youth who persistently wet the bed. What was immediately evident within the transcripts was that participants used “hiding the problem” (principle theme) as a means of adapting and getting on with life. Data from both the United States of America and England, indicate that the average young adult will visit a health professional once a year (Coleman et al, 2007; Berger, 2008). It became apparent to the researcher that many participants sought help in the early stages of life, via family support, and to some extent the supporting families adopted varieties of self-management strategies. The belief that they were participating in the management of their own condition was important to both participant and family. It was quite astonishing how these young adult males continued to function in the “real world” with such a chronic and sensitive health problem. Of great interest to the researcher was the varying impact that it had during the developmental stages of pre-adolescence, (hiding the problem within the family), adolescence, (struggling with the problem), and young adulthood and the related social isolation.

In the pre-adolescent years, the problems mostly encountered were those that involved sleep-overs and school camps. There was a growing awareness within the participants that their peers did not wet the bed, however they indicated a strong belief that they would “grow out of their problem”. Family support played an important role in getting all participants through this torrid time. The belief that it would end was nurtured by the dominant female (mother or grandmother) in the

family unit who offered the most support, according to participants, cleaning up after their bedwetting and shielding them from further embarrassing situations. Parents were often frustrated by observing the feelings of anger, shame, low self-esteem, social inadequacy and sudden mood changes in their teenagers with persistent bedwetting. This can increase parental anxiety due to the limitations imposed by their child's problem "illness" (Del Gado et al., 2005). What was most distressing in this period of the participant's life was the constant pressure to make excuses for not being part of the fun times that go with sleeping over, for the fear of being "discovered". Despite the indifference of some family members, this was the safest time in the participant's lives with strong maternal support and the belief of a cure.

Adolescence was the period identified as when the greatest struggle took place. During adolescence participants had to continue to live with, and take ownership of their problem. As previously mentioned, adolescence is a time when relationships with peers are established, along with the individual's identity. All participants spoke of conflicting feelings, referring to how they fitted into society and how it was a constant struggle to devise new strategies to ensure they were not found out. For a number of participants sporting activities featured prominently in their lives and these were often a source of challenge. The participants had very little, if any, knowledge of the mechanisms and causes of bed wetting. At times many believed it was their own fault. Bedwetting led to feelings of embarrassment and shame, low self-esteem and a lack of confidence. Bedwetting generally limited participant's social activities. As in their younger years, they also felt the continuing indifference of family members, especially their father. They felt isolated from both peers and family at this time in their lives, feeling generally alone.

Stories that were told of the participants' emerging adulthood, often including the issue of social isolation, were devastating for the researcher to hear. One young man described his belief that he felt he may have developed a different personality altogether if he had not been a "bed-wetter". This strongly emphasised the immense psychological impact that this chronic problem had on this group of young men. Of great significance for these young men was the fact that their friends expressed concern for their, fluctuating moods and increasing social isolation. It was not possible to hide it altogether. One can only begin to imagine the many and varied strategies and the untruths that these young men had to endure. This led to guilt, shame, and ongoing psychological trauma.

In perhaps the saddest account of all, one young man stated that he had chosen not to enter into an intimate relationship, as he felt he could not marry and father children due to the fact that bedwetting may be a genetic disorder and he "did not want anyone to suffer as he had". Overall, only two participants had had some success with sexual relationships, demonstrating that body image and self-concept were both adversely affected.

5.2 Relationship to extant literature

There have been many unanswered questions about the consequences of persistent bedwetting in young adulthood. In the published reports of two very large epidemiological studies in recent years (Yeung et al., 2004; Hirasing et al., 1997) the authors made mention of the consequences of adult bedwetting, such as impact on careers, social life, psychosocial well being, and personal relationships. Other than these accounts, to this researcher's knowledge this is the first phenomenological

study wherein participants' have related their stories of living a "veiled life style". A life-style punctuated by: extreme embarrassment in front of family members as well as friends; very low self esteem and self-concept; withdrawal from all social activities, including sporting events; a fear of, and great reluctance to engage in intimate relationships; and the fear of fathering a child and possibly passing the condition on to future generations. The social stigma associated with bedwetting may be two fold. Firstly, society labels the bed wetter, and secondly although they feel they maintain their "secret", this is often referred to by Goffman (1963) as discredited, as evidenced by the person's behaviour, (failure to accept personal invitations, join football tours) or that where the stigmatising attributes are not evident, commonly referred to as discreditable. One way or the other the behaviour or reputation is discrediting and can cause an individual to feel rejected, stereotyped and undesirable (Goffman, 1963).

There is some evidence in this study that the impact of bedwetting on development during the transition through adolescence to young adulthood may be as significant as that of having a recognised chronic illness or disability. It is very unlikely that these young men will have good mental health as evident in engagement in work or study, achievement in sport and hobbies, a wide group of friends, close friends, intimate friend(s), and reasonable relationships with parents (Jessor, 1993). While the issue of risk-taking behaviour, including alcohol and substance use was not explored in the present study, it is justifiable to suggest that these young men may be at increased risk. As with those who have a chronic illness or disability, the greatest issue for the young men who wet the bed is that of being seen to be different from their peers (Weisz & Hawley, 2002). Having a chronic illness means being different

from the general population and having to deal with the stigma illness brings (Fillingham & Douglas 2004). This further accentuates the social and cultural construction of bedwetting. It would not be such an issue if urination were not such a taboo subject, as it is in modern Western societies where some people are almost obsessed with the desire for personal hygiene and pleasant odours (Getcliffe & Dolman, 2007).

In discussing health professional awareness, it is important to recognise that the decision to seek treatment for bedwetting is difficult, related to the fact that there is a severe social stigma associated with this disorder, and few young adults seek treatment or readily admit to bedwetting when questioned in a general medical examination. In general, treatment is not sought until the parent believes that their child is not lazy or experiencing psychosocial difficulties (Ward-Smith & Barry 2006; Vandersteen & Husmann 1999). Many parents and medical practitioners adopt a “wait and see” approach to treatment in the belief that the problem is harmless and will spontaneously resolve. There is evidence that medical practitioners lack motivation in the time that it takes to treat and support the child and family with bedwetting (Yeung, Sreedhar, Sihoe, Sit, & Lau 2006; Lottman & Alovera, 2008). Neild & Kamat (2004) suggest that medical practitioners should take bedwetting more seriously and dispel any myths that the parents may believe, such as myth that it is simply due to the child’s poor behaviour. However, before health professionals will begin address the problem of bedwetting appropriately, and sufferers feel they have somewhere to go with this problem which currently remains hidden, bedwetting must be recognised as a significant health issue on both State and Commonwealth Government agendas.

There remain unanswered questions about the full impact of bedwetting on young adults. This study has not elucidated the depth of psychological trauma bedwetting may cause and its ultimate life-long consequences. It would seem that those who work in the field have learnt little from the personal paper submitted in the Lancet (Degraaf, 1992) that gave an overview of a bed wetter who had sought assistance for his problems from general practitioners, urologist, psychologists, neurologists and the alternative health fields, to finally at the age of 41 years find a cure with the use of current medications.

5.3 Implications of the study

The following practical implications arise from this phenomenological study: 1) The recognition of the impact that bedwetting has on the psychosocial well being of young adults, who due to the lack of education and health services in the community, do not seek help for a potentially curable problem; 2) The need for change in current clinical practice to create an assessment and management pathway for adult sufferers of bedwetting in a non-threatening environment; and 3) The urgent need for an awareness and education campaign for both health professionals and the general public. Furthermore, the study has identified that bedwetting has a similar impact to chronic illness and disability and that it must be taken more seriously, particularly in light of the potential risk of mental health problems, such as depression.

5.3.1 Implications of the psychosocial impact

Nurses have been talking about the care of the “whole” person for a very long time. The notion that health is a state of complete physical, mental, and social well-being is enshrined in textbooks and taught in schools of nursing. And yet, this clarion call is seldom put into practice in the clinical setting. What many nurses, and other health professionals who claim to care for their patients, fail to understand is that it is the person and their experience of the illness that is most important, not the illness itself. This study has shown that bedwetting, which is often dismissed as nothing more than a nuisance, like acne or short stature, can seriously affect health and normal development. Perhaps the worst outcome, which is due to societal expectations rather than the bedwetting, itself, is that the young adults who wet the bed feel very alone. They feel very alone at a time in their lives when they are in the process of making the most important developmental transition, from childhood to adulthood. These people are unable to achieve the desired milestones of friendships and intimate relationships outside of the family of birth which are necessary for normal adult functioning. The feeling of being alone is compounded by the fact that they have also distanced themselves from family members, their usual sources of support. Not only are these young adult bed wetters likely to be more prone to anxiety and depression, (Andersen & Teicher, 2008; McLennan, 1997), but they will also be a high risk for suicide (Posner, Melvin & Stanley, 2007).

5.3.2 Implications for changes in current clinical practice

It is clear that the health needs of a 10 and a 20 year old with bedwetting differ substantially, as should the services required to care for them. Currently in Western Australia, as with other States in Australia and in many developed countries

throughout the world, bedwetting programs are available for young children and their families. What is not routinely available are follow-up programs for children who relapse. And yet, for a program to be successful in the long-term it is imperative to have in place a follow-up system, because the relapse rate may be as high as 30 per cent (Butler & Holland, 2000). Relapse may be due to a physiological cause or a social cause, such as a fragmenting family unit or some other disruption to the child's usual lifestyle. Although one can advocate early intervention, it is the individual who relapses who is most at risk due to the misunderstanding in society that they will "grow out of the problem" if left alone. This myth is strong in Australian society and it is embraced by General Practitioners who play a key role as gatekeepers to the services that are available to children, adolescents and young adults who wet the bed. Other than the provision of appropriate services for those who relapse of all ages, what needs to change is the routine referral provided by General Practitioners, with a more informed assessment and referral process.

5.3.3 Implications for health professionals and the general public

The subject of incontinence, which embraces that of persistent bedwetting, requires a broader profile in medical and allied health education programs. It is understood by the researcher that there is no formal undergraduate curriculum that deals with the issue of incontinence. Furthermore, the only structured information that is routinely made available to General Practitioners is that provided by the pharmaceutical companies who specialise in medication for bedwetting. Even specialist postgraduate medical programs overlook the issue of bedwetting in young adults, because these individuals do not often seek professional medical help and the full extent of the psychosocial impact of the illness is not widely appreciated.

A great deal could be done to make health care providers much more aware of, and educated about, the appropriate assessment and management of bedwetting in young adults.

What is also required is publicity and information available to the general public about the issues of bedwetting in young adults and the avenues for people to obtain professional support. To begin with the Continence Foundation of Australia, which has both national and state branches, could publicise the topic on their promotional calendar. A national help line currently exists with well-trained staff to answer questions for sufferers of incontinence, which includes bedwetting. These people could be better informed about bedwetting in young adults. Information could be disseminated even more widely, for example, during International continence awareness week which commenced in June 2011. Weaver, Dobson & Swithenbank (2004) have previously suggested targeting teenage magazines with stories of bedwetting in adolescence. This media exposure could be extended to include the TV media as there are so many current affairs programs looking for new “human interest” stories. There is also great potential to spread the word through the health curriculum in schools, which is increasingly focused on mental health issues, and, School Health Nurses are ideally placed to provide information and support in the school drop-in clinics.

5.4 Strengths and limitations of the study

Little is known in the community about this significant health problem of bedwetting in young adults, and there is no previous research that documents the lived

experience of bedwetting in young men. This little discussed subject remains hidden within society and the young men who are affected suffer in silence. The researcher's intention in using the phenomenological method was to pursue this enquiry and to disclose feelings, thoughts and behaviours in order to discover complex realities through caring. A possible limitation of the study was that the sample population was limited to the participants who were willing to make contact with the researcher. Despite an extensive advertising campaign that included radio talks, poster advertisements distributed State-wide in medical centres, and articles in both local and community newspapers, only six young men came forward. Recruitment was difficult due to the sensitivity of the research topic and numbers small, however despite this, a convenient and purposive sample was obtained and the perceptions of the participants were captured. The results report the "understanding of a phenomenon in a particular situation and are not generalizable in the same way in which quantitative studies are" to the larger population (Burns & Grove, 2007, p. 62).

5.5 Conclusion

The researcher's intention in using the phenomenological methodology was to obtain the participant's feelings, thoughts and behaviours and discover the complex realities of their experience. The method has been used successfully in this study to illuminate the hidden experiences of young men who wet the bed. It is anticipated that the results will be of great interest to medical and nursing specialists in the field, as well as health practitioners more generally, and the general public. It is sincerely hoped that the findings will reach young people who do wet the bed and that the study will have some positive impact on their lives through the understanding that they are not alone.

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BEDWETTING

Research Is Needed On This Sensitive Subject.

Haven't told a soul?
Can't move out of home?
Failed an established program?
Doubtful regarding relationships?
Unsure who to contact?

If you are male and between the ages of 18yrs and
25yrs

And continue to wet the bed at night

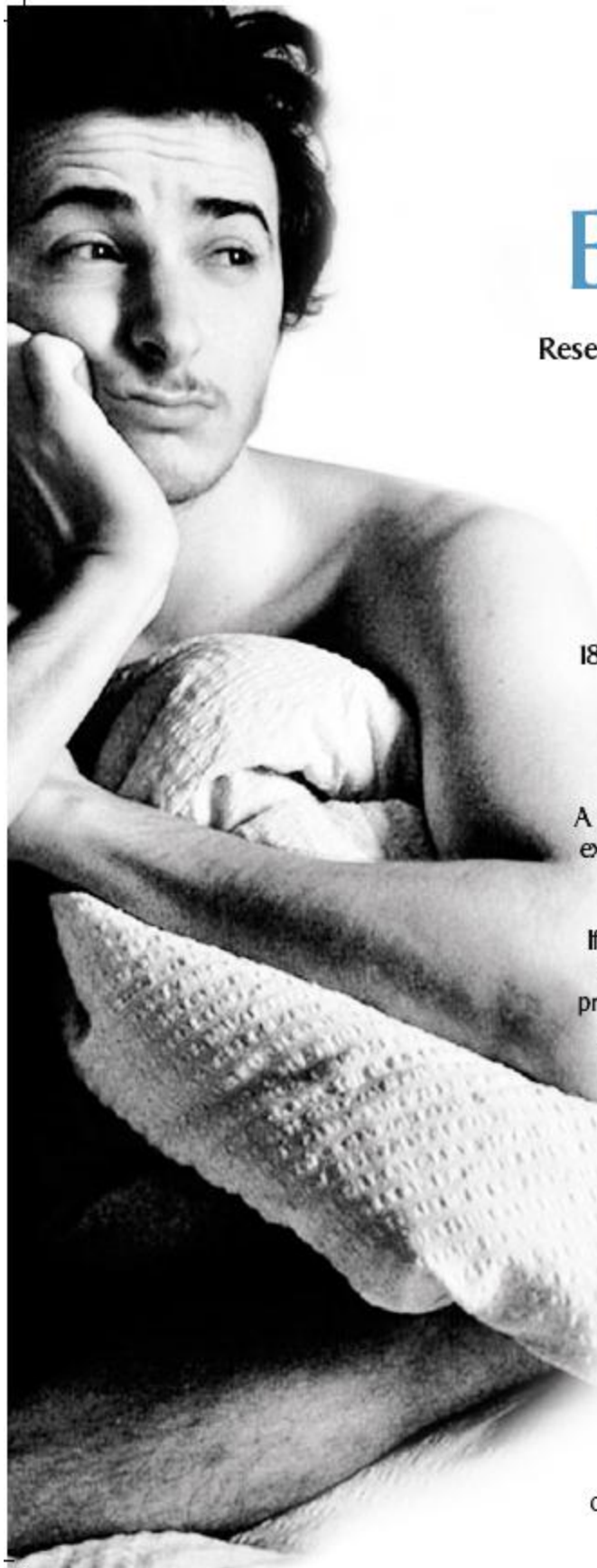
WE NEED YOUR INPUT

A study is being undertaken by researchers to explore the male experience of "bedwetting" this is called nocturnal enuresis"

If you would be willing to participate in this study and share your experience of this problem persisting in your life, please contact the researchers for more information on **0417 090 378** or e-mail Glenice Wilson on wilsong4@bigpond.net.au

YOUR EXPERIENCE WILL REMAIN CONFIDENTIAL.

This project has been approved by the Curtin Human Research Ethics Committee (HRxxxx)



Curtin 
University of Technology

Bedwetting

Research is needed on this sensitive subject.

Haven't told a soul?
Can't move out of home?
Failed an established program?
Doubtful regarding relationships?
Unsure who to contact?

If you are a male between the ages of
18 and 25 years and continue to wet the bed
at night...

WE NEED YOUR INPUT.

A study is being undertaken by researchers to
explore the male experience of "bedwetting"
called "nocturnal enuresis".

If you would be willing to participate in this
study and share your experience of this
problem persisting in your life, please contact
the researchers for more information on:

0417 090 378

or email **Glenice Wilson** on:

glenice.wilson@student.curtin.edu.au

**YOUR EXPERIENCE WILL
REMAIN CONFIDENTIAL.**

This project has been approved by the
Curtin Human Research Ethics Committee SON&M6-2007

Appendix C

INFORMATION LETTER

The Lived Experiences of Nocturnal Enuresis in Male Youth

Research Team: Glenice Wilson, Dr Garth Kendall, Dr Yvonne Hauck

Introduction

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it would involve. Please take as much time as you need to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of the study is to explore the experience and the impact of ongoing bedwetting on the life of male youth. There is no research available that directly investigates the personal experiences of bedwetting as an adolescent or young adult, on such activities as family environment, social activities educational pathways and relationships with friends, and close loved ones.

Why have I been chosen?

You have been invited to participate as your response to our recruitment indicates you are living with this issue and wish to share your experiences.

Do I have to take part?

It is your decision whether or not to take part. If you decide to take part you can still withdraw at any time, without giving a reason. If you decide not to participate, or decide late to withdraw, it will not affect any future care offered to you in respect to your further health care.

What do I have to do?

Your involvement in the study is to participate in one face-to-face interview to share your perceptions of your experiences, and how you may have felt growing up within your family environment, attending school and your social friendships. The interview will be audio-taped and carried out in the privacy of an agreed upon location such as a local library and at a time convenient for you. The interviewer is an experienced Nurse clinician in the field of Continence (Glenice Wilson), who is currently researching this health issue. It is expected that the interviews may take up to 45 minutes. A second interview may be arranged if needed and this will be negotiated between yourself and the interviewer.

Interview transcripts will not have name-identifying data on them and will be coded by a number to ensure confidentiality. Data will be stored in a locked cabinet with only the investigators having access to them.

Further questions

If you have any queries or concerns you can contact Dr Garth Kendall on 9266 2191 at Curtin University of Technology.

Concerns or complaints

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number (SON&M6-2007). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au

Appendix D

CONSENT FORM

The Lived Experience of Nocturnal Enuresis in Male Youth

Research Team: Glenice Wilson, Dr. Garth Kendall, Dr Yvonne Hauck

1. I have been given clear information (verbal and written) about this study and have been given time to consider whether I want to take part.
2. I have been able to ask questions and they have been answered to my satisfaction.
3. I understand I may withdraw from the study at any stage and withdrawal will not interfere with my future health care.
4. I agree that research data gathered from the results of this study may be published, provided that I will not be identifiable.
5. If I have any queries or concerns I know that I can contact Glenice Wilson on 0417 090 378 or 9457 3786.
6. If I have any concerns or complaints regarding this study, I can contact Dr Garth Kendall (9266 2191) on a **confidential basis**. My concerns will be drawn to the attention of the Committee who is monitoring the study. I am aware that Curtin University of Technology's Ethics committee have given ethical approval for the conduct of this study.

I consent to take part in this research project.

Name of Participant

Signature of Participant

Date

Name of Investigator

Signature of Investigator

Date

Appendix E

INTERVIEW GUIDE FOR IN-DEPTH INTERVIEWS

The Lived Experience of nocturnal enuresis in Male Youth

“PLEASE DESCRIBE WHAT IT IS LIKE FOR YOU TO BE EXPERIENCING BEDWETTING AT THIS STAGE IN YOUR LIFE?”

ADDITIONAL PROMPT QUESTIONS (if needed)

1. Can you tell me your feelings concerning growing up in the family with bedwetting?
2. Describe how this problem affected your social outings with the family such as holidays?
3. What about friends? How do you think that being a bed wetter affected your relationships with friends?
4. When you were growing up, how did bed wetting affect your involvement in social activities?
5. How has this issue affected your choice of work/higher educational pathways?
6. How has this issue affected your ability to establish personal and/or intimate relationships?
7. Describe your moods/feelings related to general health and wellbeing.
8. What influenced you to seek help (if this was the case)?
9. Can you tell me what influenced you not to seek help (if this was the case)?

Appendix F

THE LIVED EXPERIENCE OF BEDWETTING IN MALE YOUTH

Demographic Information

AGE _____

LIVING ARRANGEMENTS

- ☐ Single/living alone
- ☐ Living with spouse/partner
- ☐ Living in extended family
- ☐ Other _____

POSTAL CODE _____

HIGHEST EDUCATIONAL LEVEL

- ☐ University / college of advanced education
- ☐ TAFE / college / polytechnic
- ☐ Year 12 graduation certificate
- ☐ Attendance at high school until year _____
- ☐ Attendance at primary school until year _____

STUDENT

- ☐ Fulltime
- ☐ Part time
- ☐ Not applicable – not a student

PAID EMPLOYMENT

- ☐ Fulltime
- ☐ Part time
- ☐ Not applicable – not in paid employment

DURATION OF SYMPTOMS _____ months or years (circle correct time)

Ever dry? ☐ Yes ☐ No

HAVE YOU EVER APPROACHED A HEALTH CARE PROFESSIONAL REGARDING THIS ISSUE? (tick all that apply)

- ☐ GP
- ☐ Nurse
- ☐ Physiotherapist
- ☐ Naturopath
- ☐ Chiropractor
- ☐ Other _____

Appendix G

memorandum

To	«Glenice Wilson
From	Associate Professor Dianne Wynaden
Subject	Protocol Approval «SON&M6- 2007»
Date	5 December 2007
Copy	Associate Professor Yvonne Hauck

Office of Research and Development

**Human Research Ethics
Committee**

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL hrec@curtin.edu.au

Thank you for your "Form C Application for Approval of Research with Minimal Risk (Ethical Requirements)" for the project titled "«THE LIVED EXPERIENCE OF NOCTURNAL ENURESIS IN WESTERN AUSTRALIAN MALE YOUTH". On behalf of the Human Research Ethics Committee I am authorised to inform you that the project is approved.

Approval of this project is for a period of twelve months «5th December 2007 to «5th December 2008.

If at any time during the twelve months changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately. The approval number for your project is «SON&M6-2007. Please quote this number in any future correspondence.



Associate Professor Dianne Wynaden
Minimal Risk Coordinator
School of Nursing and Midwifery

Please Note: The following standard statement must be included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784.